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Doctoral Thesis

Stigma, perceived control and health-related quality

of life for individuals experiencing Parkinson's

disease

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Word Count

Section	Text (including abstract)	Appendices (including references)	Totals
Literature Review	7,072	3,392	10,464
Empirical Paper	6,661	3,393	10,054
Critical Appraisal	1,979	403	2,382
Ethics Section	4,003	1,694	5,697
Totals	19,715	8,882	28,597

Thesis Abstract

This thesis examined the relationship between stigma and factors of psychological wellbeing for individuals with neurodegenerative motor conditions.

Section 1 describes a systematic literature review of quantitative correlates of stigma for individuals with neurodegenerative conditions, which result in visible motor differences. Five electronic databases were searched (PsycINFO, Academic Scholar Complete, CINAHL, AMED and SCOPUS) on the 17th November 2017 to identify relevant literature. Free word searches relating to stigma and the neurodegenerative conditions of Parkinson's disease (PD), motor neuron disease/amyotrophic lateral sclerosis, Huntington's disease and multiple sclerosis were conducted. The findings indicate that stigma is related to condition severity, psychological factors, and perceptions of

health-related quality of life. Future research should statistically examine the role between stigma and demographic, social and clinical variables using more complex models to determine if bidirectional relationships exist. By furthering our understanding of the relationships between stigma and these variables, clinical practice can be enhanced at an individual and community level.

Section 2 describes a study examining if the perception of control mediates the relationship between stigma and health-related quality of life and aspects of psychological wellbeing, for individuals with PD. Individuals were invited to take part in a survey online, or in a paper format on request. Data were then analysed using mediational regression models. The findings from this sample indicated that control mediates the relationship between stigma and health-related quality of life,

depression and positive affect. These findings suggest that control may be an important factor to consider when developing interventions that are designed to reduce stigma or increase wellbeing.

Section 3 presents a critical appraisal of the research project, including its development and a detailed discussion of strengths and limitations and personal reflections.

Declaration

This thesis was conducted as part of the Doctorate in Clinical Psychology at Lancaster University, between June 2017-August 2018. The work submitted is my own and does not contain the work of any other authors. The work has been submitted for the examination of one academic programme only.

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Contents

Section One: Literature Review	16
Abstract	17
Purpose.....	17
Methods	17
Results	18
Conclusions	18
Introduction	20
Stigma and its importance.....	20
Stigma and visible health conditions	24
Stigma and neurodegenerative conditions	25
Justification of this review	27
Method	30
Search Strategy	30
Appraisal of methodological quality.....	33

Results	34
Figure 1. PRISMA Flow Diagram and Search	
Strategy.....	36
Study Characteristics	37
Table 1. Characteristics of included studies	38
Study Measures	53
Summary of quality appraisal	54
Table 2. Quality Appraisal	55
Main findings	69
Demographics	69
Condition severity	72
Psychological factors	77
Health-Related Quality of Life	81
Overall HRQoL.....	82
Activities of daily living	82

	10
Pain.....	84
Sleep and Fatigue	84
Discussion.....	86
Key Findings	86
Implications and recommendations.....	94
Review strengths and limitations.....	98
Conclusion	102
References.....	104
Appendix A. Quality appraisal checklist	126
Section Two: Research paper	141
Abstract	142
Objective	142
Design.....	142
Method	Error! Bookmark not defined.
Results	143

Conclusion	143
Introduction	144
Method	151
Design.....	151
Inclusion criteria	Error! Bookmark not defined.
Participants	Error! Bookmark not defined.
Figure 1. Path diagram.....	154
Materials	154
Validated Measures	155
Predictor Variables.....	155
Mediator Variables	155
Outcome Variables.....	155
Procedure	161
Data analysis	162
Inferential analysis	163

Results	164
Table 1. Descriptive Statistics of the sample.....	165
Clinical characteristics of the sample	167
Validated measures	168
Table 2. Means, SDs and Cronbach's alpha of psychometric variables.....	168
Inferential analyses	171
Correlational analyses.....	171
Table 3a Correlates of demographic and validated measures	177
Table 3b Correlations between validated measures	177
Regression analyses.....	171
Table 4. Mediation Models with PUK as mediator	177

Table 5. Mediation Models with PUK as mediator, with covariates	171
Table 6. Mediation Models with GSE as mediator	177
Table 7. Mediation Models with GSE as mediator, with covariates	177
Model 1: Mediation Models for stigma, perceived control and HRQOL	177
Model 2: Mediation Models for stigma, perceived control and anxiety.....	177
Model 3: Mediation Models for stigma, perceived control and depression	177
Model 4: Mediation Models for stigma, perceived control and stress	177
Model 5: Mediation Models for stigma, perceived control and positive affect	177

Mediational regressions using the GSE	177
Discussion.....	193
Clinical Implications.....	197
Strengths, limitations and proposals for future research	201
Conclusion	208
References.....	210
Appendix A. Author Guidelines	227
Section Three: Critical Appraisal	236
Abstract.....	237
Study Design.....	239
Use of quantitative methods.....	239
Online participation	240
The use of validated measures	244
Personal reflections.....	246

Stigma and Disablism.....	247
Future research.....	247
Conclusion	251
References.....	253
Appendix A. Table 1. Mediation model 1 with PUKSoPC/GSE as mediator and PDQ-7 as outcome variable.....	256
Section Four: Ethics	258
Ethics application	260
Protocol	290
Figure 1. Online survey	314
Figure 2. Approval letter	343

Section One: Literature Review

Correlates of stigma in individuals experiencing neurodegenerative conditions with motor components: A systematic quantitative review

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Abstract

Purpose

Individuals with neurodegenerative conditions that result in visible motor differences often experience stigma. The aim of this paper was to review systematically correlates of stigma for adults with progressive, neurodegenerative conditions with a motor component. Parkinson's disease, Huntington's disease, motor neuron disease/amyotrophic lateral sclerosis and multiple sclerosis were considered.

Methods

Five electronic databases were systematically searched to identify relevant studies using free-word searches relating to stigma and the specified conditions.

Results

Twenty quantitative research papers were eligible for review. Only studies reporting on Parkinson's disease and multiple sclerosis were suitable for inclusion.

The findings indicate that stigma was related to condition severity, psychological wellbeing and perceptions of health-related quality of life. The most strongly supported finding indicates that higher experiences of stigma are associated with increased anxiety and depression.

Conclusions

Future research should use complex models to examine if the relationship between stigma and health-related quality of life, and stigma and emotional wellbeing is bidirectional. This knowledge may help guide intervention delivery and ensure the cost-effective use of

psychological resources. For instance, interventions which target stigma at a societal level may improve psychological wellbeing in those with neurodegenerative conditions. Equally, effects of stigma may be considered at an individual level by targeting anxiety and depression in this population. This in turn may help to improve health-related quality of life for these individuals.

Keywords: stigma, health-related quality of life, wellbeing, demographic, neurodegenerative, Parkinson's disease, Huntington's disease, motor neuron disease/amyotrophic lateral sclerosis, multiple sclerosis, anxiety, depression, stress, condition severity.

Stigma and its importance

Stigma was defined in Goffman's (1963) seminal work as a feeling of being discredited by others for attributes that a person possesses. Since then, the concept has been researched from various perspectives including sociological, anthropological and psychological (Bos, Pryor, Reeder & Stutterheim, 2013; Scambler, 2006). This has led to the concept being redefined by a number of authors in an attempt to incorporate all aspects of the process of feeling stigmatized and devalued. For example, Link and Phelan (2001, p. 377) argue that stigma "exists when elements of labelling, stereotyping, separating, status loss and discrimination co-occur in a power situation that allows these processes to unfold"; thus, the authors acknowledge the relational context in which stigma may occur.

Both definitions provided above acknowledge the fact that individuals may feel a sense of stigma if they believe that they have characteristics that are less valued than the social norm. A number of characteristics may lead an individual to experience stigma. These can include ethnicity, gender, disability, sexual orientation and presence of illness (Campbell & Deacon, 2006).

The social context is an important determinant in how individuals who possess these characteristics are appraised (Crocker & Major, 1989). Individuals who have less valued characteristics may experience negative reactions from others (Jones, Farina, Hastorf, Markus, Miller, & Scott, 1984) such as being treated in a derogatory manner, being stared at, questioned, or insulted (Rao, Choi, Victorson, Bode, Peterman et al., 2009). Such direct experiences are known as enacted stigma (Scambler, 1989). For individuals who have

visible differences, their awareness of discriminatory views and negative stereotypes may result in feelings of embarrassment, feeling less valued or fearing future stigma experiences. Such indirect experiences are known as perceived stigma (Scambler, 1989).

In a condition with a visible component such as epilepsy, stigma has been shown to impact on an individual's quality of life and emotional wellbeing (Jacoby, 2002).

Stigma has been shown to be associated with a number of demographic, physiological and psychological components for people with epilepsy (Baker, Eccles, & Caswell, 2018). For example, experiencing epilepsy at a lower age was associated with high reports of stigma (Baker et al., 2018). Furthermore, stigma was a significant predictor of anxiety and depression for those with this condition (Baker et al., 2018). This previous

review therefore indicates the impact of stigma for individuals experiencing a visible health condition.

Experiencing stigma (perceived or enacted) may result in an individual isolating themselves or feeling excluded (Maffoni, Giardini, Pierobon, Ferrazzoli & Frazzitta, 2017). Withdrawal may lead to a loss of meaningful activity and sense of personal identity. This may increase negative affect, depression and anxiety (Simpson, McMillan, & Reeve, 2013). The impact of stigma goes beyond the individual and its effects can be felt at a systemic level, affecting intimate and wider social relationships (Laryea & Gien, 1993).

Stigma experience also impacts interpersonal relationships within the health care system (Hatzenbuehler, Phelan & Link, 2013). Experiencing stigma from health care professionals is associated with

the anticipation of future stigma experiences (Earnshaw & Quinn, 2012). Individuals who anticipate stigma may be less likely to seek support from healthcare services which may result in poor health outcomes (Earnshaw et al., 2012).

Stigma and visible health conditions

It has been suggested that individuals who possess characteristics that are less valued and which are highly visible, experience a greater level of stigma than those whose differences are less overtly identifiable (Joachim & Acorn, 2000; Goffman, 1963).

For individuals with health conditions with visible differences, a number of factors have been suggested which impact social relationships through stigma (Jones et al., 1984). From an evolutionary perspective, appearance indicates a degree of 'fitness' or

acceptability. When a person differs from the social norm, they may be considered less acceptable. If a person with a health condition has visible signs of difference, they may wish to conceal these in order to appear more in line with the social norm. When an individual has a sense of control over the visibility of their condition, they may experience less stigma (Jones et al., 1984). For individuals with progressive conditions, controllability and concealability decreases over time. As symptoms progress, conditions may become more visible and stigma experiences may increase (Jones et al., 1984).

Stigma and neurodegenerative conditions

While people with a wide range of health conditions can experience stigma, it is especially relevant in people with neurodegenerative conditions. For example, Parkinson's

disease (PD), Huntington's disease (HD), motor neuron disease (MND)/amyotrophic lateral sclerosis (ALS) and multiple sclerosis (MS) often produce visible symptoms, such as tremor, jolting, uncontrolled movements and speech difficulties. These neurodegenerative conditions are incurable and are likely to progress unpredictably (Rao et al., 2009). Moreover, they can affect all types of movement, from gross to fine motor skills, facial expressions, speech production and eating (Tickle-Degnen & Lyons, 2004).

Individuals with these neurological conditions may find everyday tasks more difficult and may require aids or assistance from others. The resulting visible differences is related to the experience of stigma for individuals with PD (Ma, Saint-Hilaire, Thomas & Tickle-Degnen, 2016), MND/ALS (Hugel, Grundy, Rigby & Young, 2006), HD

(Pringsheim et al., 2012) and MS (Grytten & Måseide, 2006).

Justification of this review

Previous reviews have examined the effects of stigma in a number of health conditions such as: HIV, (Holzemer et al., 2009) epilepsy, (Baker et al., 2018; Jacoby, 2002) and dementia (Bunn et al., 2012).

This will be the first known review to explore the correlates of stigma for progressive neurodegenerative conditions with a motor component e.g. PD, HD, MS and ALS/MND.

There is growing research exploring the correlates of stigma in the aforementioned conditions. Demographic factors such as age have been shown to be related to stigma (Carod-Artal, Vargas & Martínez-Martin, 2007).

A previous study has also found stigma experience to be

associated with condition severity (Cano-de-la-Cuerda, Vela-Desojo, Miangolarra-Page, Macías-Macías, Muñoz-Hellín, 2011). Therefore, stigma and its relationship to unmodifiable variables such as age, gender and condition severity were examined in this review.

A number of studies have found a relationship between high reports of stigma and reduced psychological wellbeing, measured using anxiety and depression scales, in PD and MS (Valvano et al., 2016; Martínez-Martín, Serrano-Dueñas, Vaca-Bquero, 2005). Stigma was found to be a significant predictor of health-related quality of life (HRQoL) in a study by Valvano for individuals with MS (Valvano et al., 2016).

Systematically reviewing the literature will allow for a greater understanding of the relationships between stigma and demographic, clinical and HRQoL factors.

This will further the understanding of the correlates and predictors of psychosocial outcomes for individuals with neurodegenerative conditions with a visible, motor component. These results may help to inform effective intervention strategies that aim to reduce the prevalence of stigma and its effect on these individuals.

In summary, this paper aimed to review systematically quantitative research exploring the correlates and predictors of stigma for individuals with such neurodegenerative conditions.

Method

Search Strategy

Relevant studies were identified for review through a systematic search of five electronic databases in November 2017: PsycINFO, Academic Search Complete (ASC), Cumulative Index to Nursing & Allied Health Literature (CINAHL), Allied & Complementary Medicine Database (AMED) and SCOPUS. The databases were selected in consultation with an academic librarian for their focus on psychological, sociological and medical studies. Focused search terms were generated based on the review question and consisted of “stigma”, “Parkinson’s disease”, “motor neuron disease”, “amyotrophic lateral sclerosis”, “Huntington’s disease” and “multiple sclerosis”. A broad search strategy using a free text search was used to ensure that all relevant literature was captured. The

subject librarian was consulted regarding this search process and confirmed that this strategy would produce the most comprehensive search of the literature.

“Stigma” was not expanded with the truncation symbol to include broader terms such as “stigmatized” or “stigmatising” due to the specific nature of this review.

The searches were restricted to peer-reviewed literature and the English language. Duplicates were removed and the titles and abstracts of the remaining papers were then screened to determine suitability for this review using the title, abstract or full text, excluding articles according to research design, methodology and sample population. Handsearching was carried out on included papers and a Google Scholar search was conducted to ensure inclusion of all relevant articles. Full text articles were assessed and included if a correlation or regression of stigma (scale or subscale) was present

against demographic, social or clinical factors. A paper by Maffoni et al., (2017) was excluded due to its qualitative research design, although stigma and its associated relationships were reviewed in the study.

This process was carried out by the author. The following inclusion criteria were applied and papers that did not meet these were removed:

- Studies used quantitative methodology.
- Studies including participants who had a diagnosis of PD, MND/ALS, HD or MS.
- Studies including a measure of stigma (scale or subscale) that was correlated with demographic, social or clinical factors.

The exclusion criteria consisted of:

- Studies using qualitative designs.
- Intervention studies.

- Studies where stigma was measured but not correlated with demographic, social or clinical factors.
- Studies that focused on individuals with the HD gene but at the pre-symptomatic phase as at this point there would be no easily discernible physical difference.
- Non-English papers.

Appraisal of methodological quality

All twenty studies were cross-sectional in design. A design-appropriate National Institute for Clinical Excellence (NICE) recommended quality appraisal tool was used (see Appendix A): The 'Graphical appraisal tool for epidemiological studies' (GATE; Jackson et al., 2006). An appraisal form derived from this tool was used to evaluate the study in four areas, including population

(e.g. “Was the method of selection of participants from the eligible population well described?”), method of selection of exposure (e.g. “How was selection bias minimised?”), study outcome (e.g. “Were the outcome measures and procedures reliable?”) and statistical analyses (e.g. “Was the study sufficiently powered to detect an intervention effect if one exists?”; Jackson et al., 2006). Methodological quality was assessed and given one of five ratings: ‘++’ (the study has been designed to minimize bias); ‘+’ (the study may not have addressed all potential sources of bias); ‘–’ (significant sources of bias may be present); ‘NR’ (not-reported); ‘NA’ (not-applicable; Jackson et al., 2006).

Results

The search produced a total of 580 papers including duplicates. Handsearching of relevant papers and

searching using Google Scholar identified 3 further studies. Therefore, a total of 583 papers were collated for review. After duplicates were removed, 295 papers were screened using the title and abstract in line with the inclusion criteria. If stigma was not mentioned as a correlate or predictor of another variable records were removed, leaving 87 articles which were screened using the full-text, again in line with the inclusion criteria. Twenty studies met the inclusion criteria, and justifications for exclusion of preliminary identified papers are presented in Figure 1.

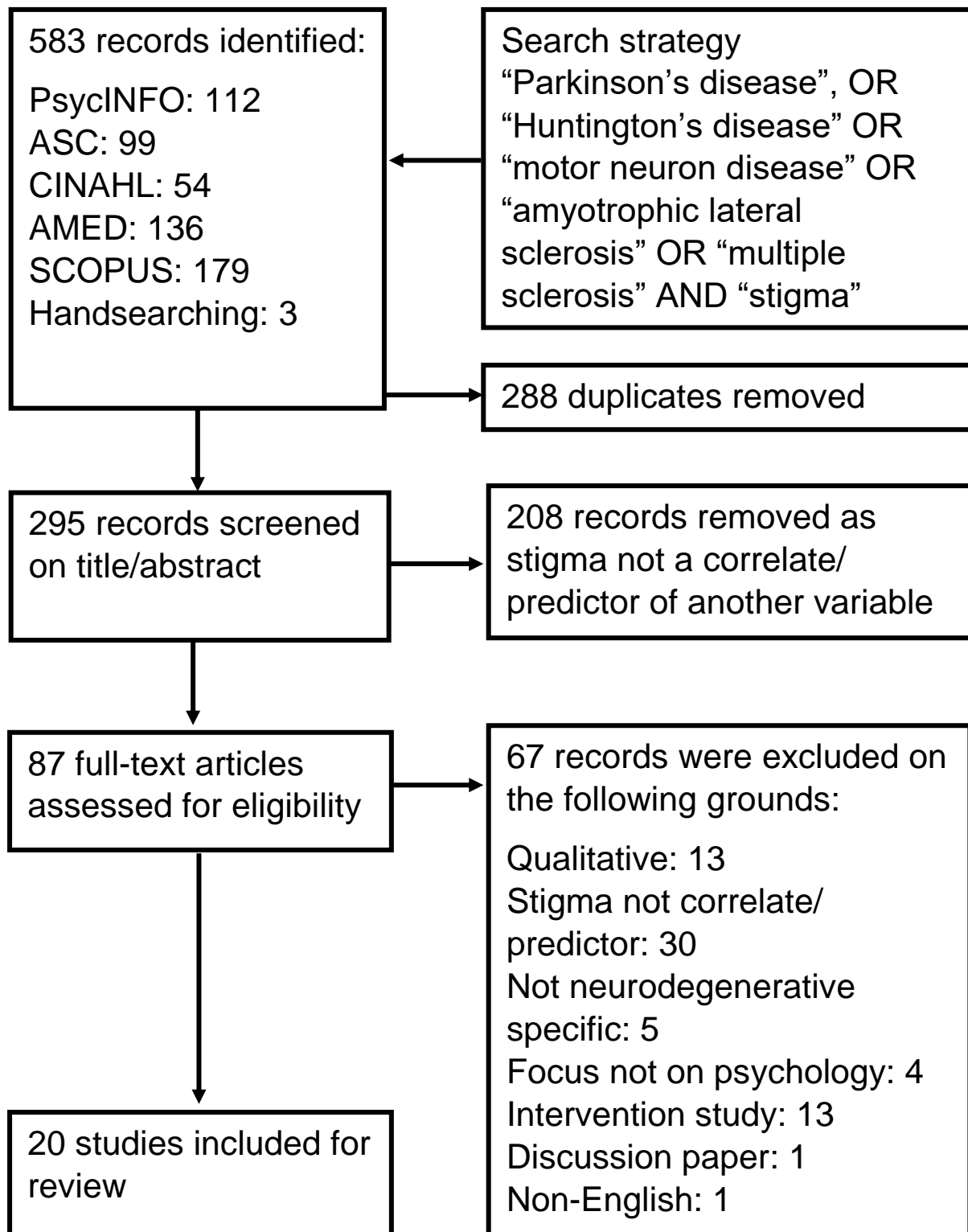


Figure 1. PRISMA Flow Diagram and Search Strategy

Study Characteristics

An overall review of the included studies can be seen in Table 1 which includes key features of each study's sample, design, measures used and overall findings, including p values, r values and β values.

Table 1. Characteristics of included studies

Study	Design and Analysis	Sample and Setting	N (% female)	Mean age (SD; age range)	Method of verifying condition	Stigma Measure	Summary of results relating to factors associated with stigma
Airlie, Baker, Smith & Young, 2001 [UK]	Cross-sectional & correlational	People with MS recruited through out-patient clinic	93 (79)	45 (11; 22-76)	Neurologist confirmed diagnosis	SEQ [12 items]	Significant correlations were found between stigma and: total self-efficacy scores ($r = -.29$), control subscale ($r = .24$), personal agency subscale ($r = -.31$).
Cano-de-la-Cuerda et al.,	Cross-sectional & correlational	Individuals with PD, recruited from	36 (19)	62 (11; NR)	United Kingdom Parkinson's Disease	PDQ-39 [4 items]	Stigma significantly correlated with trunk rigidity: at 30° extensions ($r = .14$) and flexors ($r = .45$);

2011 [Spain]		outpatient clinic			Society Data Bank		at 45° extensions ($r = .10$) and flexors ($r = .04$); at 60° extensions ($r = .09$) and flexors ($r = .12$).
Carod-Artal et al., 2008 [Brazil]	Cross sectional & regression	Individuals with PD, recruited from an outpatient clinic.	115 (44)	63 (12; NR)	Neurologist confirmed diagnosis	PDQ-39	Stigma was correlated with the following factors: SCOPA-MS I ($r = .23$), SCOPA-MS III ($r = .22$) SCOPA TOTAL ($r = .23$), CISI PD ($r = .28$), HADS-A ($r = .41$), HADS-D ($r = .32$), SCOPA PS-SI ($r = .53$).
Carod-Artal et al., 2007 [Brazil]	Cross sectional & regression	Individuals with PD, recruited from an	144 (47)	62 (11; NR)	Neurologist confirmed diagnosis	PDQ-39	Correlations were found between stigma and age ($r = -.20$); stigma and education in years (r

		out-patient clinic.					value not provided but reported in a range between -.20 to -.27).
Dubayova et al., 2009 [Slovak Republic]	Cross sectional & regression	Individuals with PD, recruited from 5 hospitals and 19 out-patient neurology clinics	153 (48)	68 (9; NR)	United Kingdom Parkinson's Disease Society Data Bank	PDQ-39	Significant correlations were found between stigma and the following variables: male CD ($r = .24$), male DS ($r = .29$), female neuroticism ($r = .30$).
Gallagher, Lees, Schrag, 2010	Cross sectional & regression	Individuals with PD, recruited from	94 (31)	68 (10; NR)	Information from Queen Square	PDQ-39	Stigma correlated with the following factors: SCOPA-AUT thermoregulatory total ($r = .41$), Motor

[UK]		Out-patients clinic			Brain Bank		<p>Complications</p> <p>UPDRS IV ($r = .44$), dyskinesia ($r = .41$), FSS ($r = .36$), motor scores ($r = .37$), gastrointestinal function ($r = .25$), urinary function ($r = .28$), cardiovascular function ($r = .21$), PSQI ($r = .26$), ESS ($r = .30$), SCOPA sleep (night; $r = .34$), SCOPA sleep (day; $r = .29$), PPRS ($r = .26$), HDRS ($r = .33$), HADS-A ($r = .31$), HADS-D ($r = .33$), FSS ($r = .36$), PVAS ($r = .35$).</p>
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Hechtner et al., 2014 [UK, France, Germany, Italy and Spain]	Cross-sectional & linear regression & secondary data	Secondary data individuals with PD; clinical setting	787 (44)	67 (10; NR)	Physicians confirmed diagnosis	PDQ-39	Stigma predicted biphasic dyskinesia ($\beta = 12.6$). Stigma predicted QoL for France ($\beta = 13.6$).
Herlofson & Larsen, 2003 [Norway]	Cross-sectional & correlational	Individuals with PD, outpatient clinic	66 (62)	71 (10; NR)	Clinical diagnosis from Neurology hospital data base	PDQ-39	No significant relationships reported.
Jesus-Ribeiro, Vieira, Ferreira, Januário	Psychometric validation &	Individuals with PD, outpatient clinic	100 (58)	66 (9; NR)	Diagnosis of PD by clinicians at Queen Square	PDQ-39 and PD QoL Quest-	Significant correlations were found between the stigma dimension of PDQ-39 and the SF-

& Freire, 2017 [Portugal]	correlational				Brain Bank UK using PDS Brain Bank Criteria	ion-naire	36 dimensions of bodily pain ($r = -.23$), social functioning: ($r = -.30$), and mental health (e.g. anxiety and depression; $r = -.43$).
Klepac et al., 2007 [Croatia]	Cross sectional & regression	Individuals with PD, outpatient clinic	111 (53)	66 (11; NR)	Confirmed diagnosis UK PD Society Brain Clinical criteria	PDQ-39	Stigma was a significant negative predictor of quality of life for individuals in a rural life setting (compared to urban dwellers; $\beta = 3.64$).
Looper & Kirmayer, 2004 [Canada]	Linear regression & correlational	Individuals with MS, Specialty Clinic in	33 (73)	42 (11; NR)	Clinically diagnosed MS participants	Attitudes of Other Scale Derived	Stigma was correlated with depression ($r = .40$) and CD ($r = -.34$). Stigma was a significant predictor

		Univer- sity hospital				from Expla- natory Model Inter- view Cata- logue. EMIC & Pain Stig- ma Scale [22 items]	of depression ($\beta =$.54).
Luo, Tan, Li, Soh & Thum- boo, 2005	Cross- sectional & correlat- ional	Individ- uals with PD, recruited from a	63 (41)	65 (9; 41- 82)	United Kingdom Parkin- son's Disease	PDQ- 39 Chin- ese Sing-	Stigma correlated with EQ-5D scores for usual activities ($r =$.44), self-care ($r =$.46), anxiety/

[Singapore]		Hospital out-patients department			Society Brain Bank and Singapore PD Society. Others self-identified with condition	apore Version	depression ($r = .56$) and mobility ($r = .27$).
Martínez-Martín et al., 2005 [Spain]	Cross-sectional & correlational	Individuals with PD, out-patients clinic.	137 (32)	69 (10; 44-92)	United Kingdom Parkinson's Disease Society Brain Bank	PDQ-39	Significant correlations were found between stigma and the following variables: UPDRS II ($r = .37$), HADS-A ($r = .38$) and HADS-D ($r = .57$).
Penwell-Waines	Correlational	MS patients,	121 (85)	45	Clinicians at MS	9 item-stigma	Stigma significantly predicted anxiety ($\beta =$

et al., 2017 [USA]	Hierarchical linear regressions	outpatients Clinic		(11; NR)	clinic (had MS > 10 years)	scale (Reece 2003) adapted to MS	.325) and depression ($\beta = .198$).
Phu et al., 2014 [Australia]	Cross sectional & regression	Individuals with PD, outpatient clinics	100 (31)	67 (NR; NR)	Clinician diagnosed according to Queen's Square Brain Bank criteria	PDQ-39	No significant relationships found.
Simpson, Lekwuwa & Craw-	Cross sectional & regression	Individuals with PD, recruited	81 (27)	66 (8; NR)	Neurologist confirmed diagnosis	PDQ-39	Stigma was significantly correlated with the following factors:

ford, 2014 [UK]	ion analyses	from Out-patient clinics					UPDRS III ($r = .33$), PD ADLS ($r = .32$), H & Y ($r = .30$), Depression ($r = .48$), Anxiety ($r = .29$), Stress ($r = .36$), Optimism ($r = -.32$), Self-esteem ($r = -.31$).
Skorv- anek, et al., 2015 [Slovakia]	Multiple regression analyses	Individuals with PD, recruited from Outpatient clinics	291 (47)	68 (9; NR)	United Kingdom Parkinson's Disease Society Brain Bank	PDQ-39	Significant predictive relationships were found between stigma and age ($\beta = -.30$), and stigma and the following items from the UPDRS I: apathy ($\beta = .17$), depression ($\beta = .23$), and urinary problems ($\beta = .15$).

Tu, Hwang, Ma, Chang & Hsu, 2017 [Taiwan]	Cross-sectional & regression	Individuals with PD, recruited from Neurology departments of 2 medical centres	92 (35)	65 (10; 40-83)	United Kingdom Parkinson's Disease Brain Bank	PDQ-39	Significant correlations were found between stigma and UPDRS II ($r = .24$), and stigma and GDS ($r = .45$).
Valvano et al., 2016 [USA]	Cross-sectional & correlation, mediational regression	Individuals with MS, recruited from Outpatients MS	128 (85)	46 (11; NR)	Clinical diagnosis at MS clinic	9 item-stigma scale (Reece 2003) adapted to MS	Significant correlations were reported between stigma and: cognitive fusion ($r = .41$), depression ($r = .39$), anxiety ($r = .38$), HRQoL ($r = -.52$).

		Centre US					Stigma was a significant predictor of depression ($\beta = .11$) and HRQoL ($\beta = .23$). Cognitive fusion significantly indirectly mediated the relationship between stigma and: anxiety ($\beta = .22$), depression ($\beta = .11$) and HRQoL ($\beta = .14$). Depression ($\beta = .21$), anxiety ($\beta = .32$) and HRQoL ($\beta = .34$) significantly indirectly mediated the relationship between stigma and cognitive fusion.
Zhao et al., 2008	Cross sectional	Individ- uals with	183 (31)	61 (10; 30-87)	National Institute	PDQ-8	In simple linear regression, stigma

[Singapore]	& regression	PD, recruited via attendance at neuroscience clinic			of Neurological Disorders and Stroke criteria for the diagnosis of Parkinson's disease		was a significant predictor of motor scores ($\beta = 1.03$) and CD ($\beta = 1.12$). In multiple linear regression, stigma significantly predicted CD ($\beta = 1.11$).
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Note: CD: Condition Duration; DS: Disease Severity; NR: Not reported; n.s. Non-significant; CIRS-G: Cumulative Illness Rating Scale- Geriatrics; CISI PD: Clinical Impression of Severity Index for Parkinson's Disease; GDS: Geriatric Depression Scale; EQ-5D: EuroQuol-five domain questionnaire, five level response version; EQ-VAS: EuroQuol Visual Analog Scale; ESS: Epworth Sleepiness Scale; FSS: Fatigue Severity Scale; GDS: Geriatric Depression Scale; H & Y Scale: Hoehn and Yahr Scale;

HADS-A: Hospital Anxiety and Depression Scale- Anxiety; HADS-D: Hospital Anxiety and Depression Scale – Depression; HDRS: Hamilton Depression rating scale; ICRD: Impulse Control and Related Disorders; LECD: Levodopa equivalent drug dose; MDS: Movement Disorder Society; PD ADLS: Parkinson's Disease -Activities of Daily Living Scale; PSQI: Pittsburgh Sleep Quality Index; PVAS: Pain Visual Analogue Scale; S&E: Schwab & England Scale; Activities of Daily Living Scale; SCOPA PS-SI, SCOPA-MS I, SCOPA-MS III, SCOPA TOTAL, SCOPA-AUT Thermoregulatory Total - Scales for Outcomes for Individual's with Parkinson's Disease; SF-36: The Short Form (36) Health Survey; SEQ: The Self-Efficacy Questionnaire; UPDRS: The Unified Parkinson's Disease Rating Scale; UPDRS Part I: Non-motor symptoms of daily living; UPDRS Part II: Motor symptoms of daily living; UPDRS Part III: Motor examination; UPDRS Part IV: Complications of therapy

The total number of participants across all 20 studies was 2,928. This included 2,553 individuals with PD (87% across 16 studies) and 375 individuals with MS (13% across 4 studies). No results were found for HD and MND/ALS populations. The average number of participants per study was 52.

Only five studies reported an age range; using these studies, an age range of 22-92 years was present. All studies reported a mean age. A weighted mean age for the total number of participants within each study was calculated for the PD studies (weighted mean = 66 years) and MS studies (weighted mean = 45 years).

Studies were conducted worldwide and included Europe, North and South America, Asia and Australia (see Table 1 for details). Three studies were conducted in the UK. One study was carried out across five

European countries, including the UK, France, Germany, Italy and Spain. Of ten studies, two were carried out in each of the following countries: Spain, Brazil, Slovakia, Singapore and USA. The remaining countries included Norway, Croatia, Portugal, Canada, Australia and Taiwan, of which, one study was conducted in each country. All of the studies were of cross-sectional design, with 14 employing regression analyses and 6 implementing purely correlational analyses.

Study Measures

A total of five different measures of stigma were used across the 20 included studies (see Table 1 for details). Fifteen studies used the well-validated PDQ-39 scale (Jenkinson, Fitzpatrick, Peto, Greenhall & Hyman, 1997) to measure stigma in PD; in this general HRQoL scale,

stigma is measured using a thirty-nine-item subscale.

One study used a single item from the PDQ-8

(Jenkinson & Fitzpatrick, 2007) and another study used

the Self Efficacy Questionnaire (Tedman, Thornton, &

Baker 1995) for MS. One study used the Attitudes of

Others Scale, adapted from the Explanatory Model

Interview Catalogue (Weiss et al., 1992) and the Pain

Stigma Scale (Lennon, Link, Marbach & Dohrenwend,

1989). Lastly, two studies used the nine-item Stigma

Scale (Reece, 2003), adapted for MS.

Summary of quality appraisal

An overview of the methodological quality of the papers

used in this review is included in Table 2.

Table 2. Quality Appraisal

Study	Population	Method of selection of exposure	Outcomes	Analyses	Overall Rating
Airlie et al., 2001	1.1: ++ 1.2: + 1.3: + Overall: +	2.1: –, – 2.2: ++ 2.3: NA 2.4: NR 2.5: ++ Overall: +	3.1: – 3.2: + 3.3: NA 3.4: NA 3.5: NA Overall: –	4.1: NR 4.2: NR, + 4.3: ++ 4.4: ++, – Overall: +	IV: + EV: +
Cano-de-la-Cuerda et al., 2011	1.1: –, + 1.2: +, +, – 1.3 –, NR, + Overall: –	2.1: NR, NR 2.2: +, +, 2.3: NA, NA, NA	3.1: NR, +, NR, + 3.2: ++, ++ 3.3: +, NA, NA 3.4: NA, NA, NA	4.1: NR, NR, NR 4.2: ++, –, 4.3 ++, NR	IV: + EV: –

		2.4: NR, –, – 2.5: +, + Overall: +	3.5: NA, NA, NA Overall: +	4.4 ++, ++, NR Overall: ++	
Carod-Artal et al., 2008	1,1: ++, + 1.2: –, ++, – 1.3: –, ++, – Overall: –	2.1 NR 2.2 + 2.3 NA 2.4 NR, ++, ++ 2.5 NR, + Overall: +	3.1: NR, –, NR, + 3.2: –, ++ 3.3: ++, NA, NA 3.4: NA, NA, NA 3.5: NA, NA, NA Overall: NA	4.1: NR, NA, NR 4.2: ++, ++ 4.3: ++, NR 4.4 ++, NR, NR Overall: ++	IV: ++ EV: –
Carod-Artal, et al., 2007	1.1: ++, + 1.2: – –, +, – – 1.3: NR, ++, NR, – –	2.1: – – 2.2: ++, ++ 2.3: NA, NA	3.1: NR, – –, NR, +, + 3.2: ++, ++ 3.3: ++, NA, NA	4.1: NR, + 4.2: ++, + 4.3: ++, NR 4.4: ++, + NR	IV: + EV: –

	Overall: –	2.4: NR, – –, – – 2.5: NR, + Overall: +	3.4: NA, NA, NA 3.5: NA, NA, NA Overall: +	Overall: +	
Dubayova et al., 2009	1.1: ++, – 1.2: NR, +, ++ 1.3: –, +, ++, ++ Overall: +	2.1: NR, NR 2.2: ++, ++ 2.3: NA, NA, NA 2.4 ++, –, – 2.5: –, NR Overall: +	3.1: NR, –, + 3.2: ++, ++ 3.3: +, NA, NA 3.4: NA, NA, NA 3.5: NA, NA, NA Overall: +	4.1: NR, NR, NR 4.2: ++, – 4.3: ++, NA 4.4: ++, ++, ++ Overall: ++	IV: + EV: –
Gallagher et al., 2010	1.1: – –, – – 1.2: – –, – –, – –	2.1: NR, NR 2.2: ++, ++ 2.3: NA, NA	3.1: NR, +, NR, NR 3.2: ++	4.1: NR, NR 4.2: ++, + 4.3: ++, NR	IV: + EV: –

	1.3: NR, --, NR, -- Overall: --	2.4: --, --, -- 2.5: ++, ++ Overall: ++	3.3: ++, NA, NA 3.4: NA, NA, NA 3.5: NA, NA, NA Overall: +	4.4: ++, +, NR Overall: ++	
Hechtner et al., 2014	1.1: + 1.2: ++ 1.3: ++ Overall: ++	2.1: NR 2.2: ++ 2.3: NA 2.4: - 2.5: ++ Overall: +	3.1: ++, - 3.2: NA 3.3: NA 3.4: NA 3.5: NA Overall: +	4.1: - 4.2: + 4.3: + 4.4: ++ Overall: +	IV: + EV: ++
Herlofson & Larsen, 2003	1.1: +, +	2.1: NR, NR 2.2: ++, ++	3.1: +, -, -, - 3.2: ++, ++	4.1: -, - 4.2: ++, +	IV: - EV: -

	1.2: NR, ++, + 1.3: –, ++, +, ++ Overall: –	2.3: NA, NA, NA 2.4: +, –, – 2.5: NR, NR Overall: +	3.3: –, NA 3.4: NA, NA, NA Overall: –	4.3: ++, – 4.4 –, NR, NR Overall: –	
Jesus- Ribeiro et al., 2017	1.1: +, + 1.2: +, ++, NR 1.3: NR, ++, NR, + Overall: +	2.1: NR, NR 2.2: ++, ++ 2.3: NA, NA, NA 2.4: NR 2.5: NR, –, – Overall: +	3.1: ++, –, +, ++ 3.2: ++, ++ 3.3: NA, NA, NA 3.4: NA, NA, NA 3.5: NA, NA, NA Overall: NA	4.1: NR, + 4.2: ++, – 4.3: ++, NR 4.4: ++, ++, ++ Overall: ++	IV: ++ EV: +

Klepac et al., 2007	1.1: ++, ++ 1.2: NR, ++, NR 1.3: ++, ++, – Overall: –	2.1: NR, NR 2.2: –, – 2.3: NA, NA, NA 2.4: –, –, – 2.5 ++ Overall: –	3.1: NR, –, + 3.2: ++, ++ 3.3: ++, NA, NA 3.4: NA, NA, NA 3.5: NA, NA, NA Overall: +	4.1: NR, NR, NR 4.2: ++, – 4.3: ++, NR 4.4: ++, ++, + Overall: ++	IV: + EV: –
Looper et al., 2004	1.1: ++, ++ 1.2: – 1.3: –, +, NR, + Overall: –	2.1: NR 2.2: ++, ++ 2.3: NA, ++, NA 2.4: ++, ++, NA 2.5: NR	3.1: ++, –, +, – 3.2: ++, ++ 3.3: ++, NA, NA 3.4: NA, NA, NA 3.5: NA, NA, NA Overall: +	4.1: NR, NR 4.2: ++ 4.3: ++, ++ 4.4: ++, NR, NR Overall: ++	IV: ++ EV: –

		Overall: ++			
Luo et al., 2005	1.1: + 1.2: NR, + 1.3: NR, +, ++ Overall: +	2.1: NR, NR 2.2: +, ++ 2.3: NA, NA, NA 2.4: NR, -, - 2.5: NR, + Overall: +	3.1: ++, -, +, ++ 3.2 ++, + 3.3 ++, NA, NA 3.4: NA, NA, NA 3.5: NA, NA, NA Overall: ++	4.1: NR, NA, NR 4.2: ++, - 4.3: ++, - 4.4 ++, NR, NR Overall: ++	IV: ++ EV: -
Martínez-Martín et al., 2005	1.1: -, NR 1.2: +, -	2.1: -, - 2.2: ++, ++	3.1: ++, -, +, ++ 3.2: ++, ++ 3.3: +, NA, NA	4.1: NR, NA, NA 4.2: -, +	IV: + EV: -

	1.3: NR, –, NR, – Overall: –	2.3: NA, NA, NA 2.4: NR, –, – 2.5: NR, – Overall: –	3.4: NA, NA, NA 3.5: NA, NA, NA Overall: +	4.3: ++, – 4.4: ++, ++, – Overall: +	
Penwell-Waines, 2017	1.1: ++ 1.2: + 1.3: +, + Overall: +	2.1: – 2.2: ++ 2.3: NA 2.4: NR, NR 2.5: ++ Overall: +	3.1: – 3.2: NA 3.3: NA 3.4: NA Overall: –	4.1: NR 4.2: ++ 4.3: ++ 4.4: +, NR Overall: +	IV: + EV: +
Phu et al., 2014	1.1: – –, – – 1.2: ++, ++, – –	2.1: NR, NR 2.2: ++, +	3.1: NR, +, NR, NR 3.2: ++, +	4.1: –, – – 4.2: ++, – –	IV: + EV: –

	1.3: NR, ++, NR, ++ Overall: +	2.3: NA, NA, NA 2.4: ++, --, -- 2.5: NR, + Overall: +	3.3: +, NA, NA 3.4: NA, NA, NA 3.5: NA, NA, NA Overall: +	4.3: ++, ++ 4.4: ++, ++, -- -- Overall: +	
Simpson et al., 2014	1.1: +, + 1.2: ++, ++, ++ 1.3: ++, ++, +, ++ Overall: ++	2.1: NR, NR 2.2: ++, ++ 2.3: NA, NA 2.4: NR, +, + 2.5: ++, ++ Overall: ++	3.1: ++, --, ++, ++ 3.2: ++, ++ 3.3: ++, NA, NA 3.4: NA, NA, NA 3.5: NA, NA, NA Overall: ++	4.1: ++, NR 4.2: ++, + 4.3: ++, NR 4.4: ++, +, NR Overall: ++	IV: ++ EV: ++

Skorvanek et al., 2015	1.1: —, NR 1.2: ++, — —, ++ 1.3: ++, ++, NR, ++ Overall: +	2.1: NR, NR 2.2: ++, ++, 2.3: NA, NA, NA 2.4: ++, — —, — — 2.5: NR, — — Overall: ++	3.1: ++, — —, +, ++ 3.2: ++, ++ 3.3: ++, NA, NA 3.4: NA, NA, NA 3.5: NA, NA, NA Overall: ++	4.1: NR, NR 4.2: NR, — — 4.3: ++, ++ 4.4: ++, +, NR Overall: ++	IV: ++ EV: +
Tu et al. 2017	1.1: +, — — 1.2: +, ++, NR 1.3: +, +, NR, ++ Overall: +	2.1: + 2.2: ++, ++ 2.3: NA, NA, NA 2.4: NR, — —, — — Overall: +	3.1: ++, — —, NR, ++ 3.2: ++, ++ 3.3: ++, NA, NA 3.4: NA, NA, NA 3.5: NA, NA, NA Overall: ++	4.1: NR, NR 4.2: ++, — — 4.3: ++, NR 4.4: ++, ++, NR Overall: ++	IV: + EV: +

Valvano et al., 2016	1.1: ++, ++ 1.2: + 1.3: + Overall: +	2.1: NR 2.2: ++ 2.3: NA 2.4: NR 2.5: ++ Overall: ++	3.1: ++, -, -, NR 3.2 NR, + 3.3 +, NA, NA 3.4 NA, NA, NA 3.5 NA, NA, NA Overall: +	4.1: NR, NR, ++ 4.2: ++, + 4.3: ++, NR 4.4: ++, ++, ++ Overall: ++	IV: ++ EV: +
Zhao et al., 2008	1.1: ++, ++ 1.2: ++, ++, + 1.3: +, +, +, ++ Overall: ++	2.1: NR, NR 2.2: ++, + 2.3: NA, NA, NA 2.4: NR, -, - 2.5: ++ Overall: +	3.1: NR, +, NR, + 3.2 ++, ++ 3.3 ++, NA, NA 3.4 NA, NA, NA 3.5 NA, NA, NA Overall: ++	4.1 NR, NR, NR 4.2 +, -, 4.3 ++, NA 4.4 ++, +, NR Overall: +	IV: + EV: -

Note: EV: external validity; IV: internal validity; NA: not applicable; NR: not reported; ++: all or most of the checklist criteria have been fulfilled; + Some of the checklist criteria have been fulfilled; – Few or no checklist criteria have been fulfilled.

Overall, of the included studies in this review, 19 were rated satisfactory in terms of their overall quality. Only one study was rated as having potential sources of bias for both internal and external validity (Herlofson & Larson, 2003). However, the results of this study did not differ from that of other included papers and therefore was included as part of the review.

The extent to which the findings of the papers can be generalized to a wider population should be considered with some caution as only two of the studies received the highest rating of external validity (Hechtner et al., 2014; Simpson et al., 2014), with a further seven studies receiving satisfactory ratings (Jesus-Ribeiro et al., 2017; Penwell-Waines et al., 2017; Tu et al., 2017; Valvano et al., 2016; Phu et al., 2014; Skorvanek et al., 2015; Airlie et al. 2001). Inclusion criteria were narrow and restricted

to PD populations of mild to moderate severity, which limit the generalisability of the findings. Some studies reported narrow sample parameters excluding, for example, individuals who used walking aids (Cano-de-la-Cuerda et al., 2011), had sensory impairments (Martínez-Martín et al., 2005), or may have been illiterate (Klepac et al., 2007; Martínez-Martín et al., 2005).

The validity and reliability of measures was referenced in the majority of studies, however, supporting evidence, including Cronbach's alpha, was not consistently reported.

Only one of the included studies reported a prospective power calculation (Simpson et al., 2014), however two studies did comment on sample size limitations and

implications for findings (Herlofson et al., 2003; Phu et al., 2014).

Main findings

The findings of the study will be considered in terms of stigma's relationship with four broad factors; demographic, condition severity, psychological and HRQoL.

Demographics

Seven of the included studies examined the relationship between stigma and demographic factors such as age, gender and ethnicity (Skorvanek et al., 2015; Hechtner et al., 2014; Simpson et al., 2014; Dubayova et al., 2009; Zhao et al., 2008; Carod-Artal et al., 2007; Klepac et al., 2007).

While generally age might be considered to be a factor that correlates with stigma experience (Goffman, 1963;

Tiggemann & Lynch, 2001), with younger individuals reporting higher levels of stigma, the findings of this review vary as to whether age has an association with stigma. Carod-Artal et al. (2007) report a weak negative association between age and stigma for individuals with PD ($r = -.20$), with younger individuals experiencing higher levels of stigma. Skorvanek et al. (2015) found age to be a significant predictor of stigma when entered into a regression model ($\beta = -.30$), again with younger individuals reporting higher levels of stigma. A further PD study, Dubayova et al. (2009) found a small association for age and stigma for females of a younger age only ($r = -.22$). Non-significant findings between age and stigma were also reported (Simpson et al., 2014; Zhao et al., 2008).

The effect of gender on stigma experience was not found in this review. Three studies report no effect between gender and stigma experience (Skorvanek et al, 2015; Simpson et al., 2014; Zhao et al., 2008) and only one study reports a significant correlation (Dubayova et al., 2009). Dubayova et al. (2009) found an effect of gender in the relationship between personality type and stigma, with neuroticism and stigma correlating at a moderate effect size for women only ($r = .30$). However, it accounted for only a small proportion of the variance within the regression model when controlling for age, functional status and condition duration (adjusted $R^2 = .07$).

Other papers have examined the relationship between stigma and additional demographic factors such as ethnicity, marital status, work status, employment type,

years since diagnosis, years since symptom onset; which were all found to be non-significant (see Table 1).

The study by Klepac et al. (2007) identified living environment to be a significant predictor of stigma experience, with individuals living in rural settings reporting greater levels of stigma than urban residents.

In summary, when considering demographic variables, the review found mixed findings for the relationship between stigma and age. Stigma was not found to correlate with any other demographic variables.

Condition severity

It is argued that visibility plays a role in stigma experience (Jones et al., 1984) and as conditions progress reported stigma experience may increase.

Stigma and condition severity was found to be positively related in eight of the reviewed studies (Tu et al., 2017;

Hechtner et.al, 2014; Simpson et al., 2014; Cano-de-la-Cuerdo et al., 2011; Gallagher et al., 2010; Carod-Artal et al., 2008; Luo et al., 2005; Martínez-Martín et al., 2005). Higher stigma scores were associated with poorer autonomic functioning in two studies (Skorvanek et al., 2015; Gallagher et al., 2010). Two studies report a significant relationship between stigma and dyskinesia (involuntary movements), (Hechtner et.al, 2014; Gallagher et al. 2010). As individuals' physical symptoms increased, the higher the reported experiences of stigma. Gallagher et al. (2010) reported a correlation between dyskinesia and stigma at a medium effect size ($r = .41$). Hechtner et al. (2014) reported dyskinesia to be a significant predictor of stigma.

Movement difficulties and their relationship to stigma was examined in a number of studies (Tu et al., 2017; Skorvanek et al., 2015; Simpson et al., 2014; Cano-de-

la-Cuerda et al., 2011; Carod-Artal et al., 2008; Zhao et al., 2008; Martínez-Martín et al., 2005). Physiological decline was positively related to stigma experience in the studies by Cano-de-la-Cueda et al. (2011) and Luo et al. (2005). Cano-de-la-Cueda et al. (2011) found that physical restriction of movement significantly correlated with stigma at a medium effect size ($r = .45$). Luo et al. (2005) reported that high stigma experiences were related to poor physical mobility. The study by Simpson et al. (2014) also reports a significant relationship between motor functioning and stigma ($r = .3$), with a small-moderate effect size. In the same study, the stage of the condition correlated with stigma experience ($r = .3$). This study achieved the highest rating of ecological validity due to the inclusion of individuals spanning the condition trajectory. This contrasts with two studies which examined the relationship between the stage of

condition and stigma experience, and found no effect (Carod-Artal et al., 2008; Martínez-Martín et al., 2005).

Physician-rated motor impairments did not correlate with stigma experience in two studies (Tu et al., 2017; Martínez-Martín et al., 2005).

With increasing duration in progressive neurodegenerative conditions, visible signs of difference become more apparent over time. Findings suggest that condition duration is not related to stigma experience as two studies reported a non-significant finding for this relationship (Skorvanek et al., 2015; Simpson et al., 2014). With an increase in condition duration, comes an increase in age and a higher likelihood of experiencing illness (Bury, 1982). Perceptions of stigma may be less likely to increase in later life if having a condition is regarded typical for an individual based on age (Bury,

1982). However, two studies report a relationship between stigma and condition duration (Dubayova et al., 2009; Zhao et al., 2008). The Dubayova et al. (2009) study examined this relationship and found a significant correlation for condition duration ($r = .29$) and condition severity ($r = .24$) for males only when controlling for age, functional status and disease (Dubayova et al.; 2009). Zhao et al. (2008) reported PD duration to be a significant predictor of stigma. This study however did not provide details on any of the factors in the model which were controlled, and only individuals with mild PD were included. It is therefore possible that such a relationship exists only for those with less visible symptoms. It is important to note that the Zhao et al. (2008) study received an overall less than satisfactory rating of ecological validity. Studies that received higher scores of methodological rigor and generalisability did

not replicate the finding that stigma predicts condition duration (Skorvanek et al., 2015; Simpson et al., 2014).

Levodopa use and stigma experience is reported in one study by Phu et al. (2014) and a non-significant association was reported.

In summary, studies suggest that increasing physiological decline (i.e. increasing condition severity) is associated with higher stigma experience. There appears to be little consistency in the findings in the relationship between stigma experience and condition duration.

Psychological factors

More than half of the included papers report associations between stigma and psychological factors.

Nine studies found a significant correlation between stigma and depression (effect sizes ranged from small to

moderate, with higher stigma scores related to higher depression scores; Jesus-Ribeiro et al., 2017; Tu et al., 2017; Valvano et al., 2016; Simpson et al., 2014; Gallagher et al., 2010; Carod-Artal et al., 2008; Luo et al., 2005; Martínez-Martín et al., 2005; Looper and Kirmayer., 2004). Stigma was also found to be a significant predictor of depression (Penwell-Waines et al., 2017; Skorvanek et al., 2015). Eight of the studies found a positive relationship between stigma and anxiety, with higher stigma associated with increased anxiety (from medium to large effects; Jesus-Ribeiro et al., 2017; Penwell-Waines et al., 2017; Valvano et al., 2016; Simpson et al., 2014; Gallagher et al., 2010; Carod-Artal et al., 2008; Luo et al., 2005; Martínez-Martín et al., 2005). Three studies found non-significant relationships between stigma and anxiety/depression when measured using the UPDRS-I (Tu et al., 2017;

Skorvanek et al., 2015; Martínez-Martín et al., 2005).

However, Martínez-Martín et al. (2005) also examined the constructs of anxiety and depression in more detail, using the HADS and found significant relationships of medium and large effect size, respectively. Similarly, Tu et al. (2017) examined depression using the Geriatric Depression Scale and reported a significant relationship of medium effect. These findings suggest that the UPDRS-I may not be sensitive enough to measure anxiety and depression in this population.

There appears to be no effect for the relationship between psychosis (which includes hallucinations) and stigma experience (Skorvanek et al., 2015). A small effect was reported by Gallagher et al. (2010; $r = .26$); however, the overall methodological quality of this study

is poor and has limited generalisability to a PD population.

Where stigma was measured against other psychological factors, significant relationships have been documented for; apathy (Skorvanek et al., 2015), stress (Simpson et al., 2014) and cognitive fusion (the tendency to view thoughts as facts and perceive these as unchangeable; Valvano et al., 2016).

A limited number of the included studies examined the relationship between positive factors of psychological wellbeing and their association with stigma (Simpson et al., 2014; Airlie et al., 2001). Airlie et al. (2001) found that greater levels of stigma are associated with lower self-efficacy (one's perceived ability to overcome challenges). Simpson et al. (2014) found a non-

significant relationship between stigma experience and positive affect.

In summary, there appears to be strong and consistent findings for the relationship between stigma and measures of psychological distress, in particular anxiety and depression.

Health-Related Quality of Life

Ten of the reviewed studies examined overall HRQoL and different aspects of HRQoL, including activities of daily living, pain, and sleep/fatigue (Tu et al., 2017; Jesus-Ribeiro et al., 2017; Valvano et al., 2016; Skorvanek et al., 2015; Hechtner et al., 2014; Simpson et al., 2014; Gallagher et al., 2010; Carod-Artal et al., 2008; Luo et al., 2005; Martínez-Martín et al., 2005).

Overall HRQoL

The relationship between stigma and HRQoL was examined in two studies (Valvano et al., 2016; Hechtner et al., 2014). Hechtner et al. (2014) examined the predictive power of stigma across five European countries (UK, France, Germany, Italy and Spain) and reported that stigma was a significant predictor of HRQoL for France only, when controlling for age, gender, disease stage and duration. Similarly, in a North American study, Valvano et al. (2016) reported that stigma was a significant predictor of HRQoL when controlling for cognitive fusion.

Activities of daily living

How stigma influences activities of daily living and social roles was examined across four of the reviewed studies (Simpson et al., 2014; Carod-Artal et al., 2008; Luo et

al., 2005; Martínez-Martín et al., 2005). Consistent associations between stigma experience and activities of daily living were reported at a small to medium effect. Three studies reported a medium effect size between stigma and aspects of daily living and stigma and self-care (e.g. dressing and washing self and attending work; Simpson et al., 2014; Carod-Artal et al., 2008; Luo et al., 2005). These results indicate that higher reports of stigma are related to lower activities of daily living. Only one study reports a non-significant effect between stigma and activities of daily living (Martínez-Martín et al., 2005); however, this study included mild PD symptoms only and has limited generalisability to the PD population.

Pain

Five of the reviewed studies examined the relationship between stigma and pain; the relationship had mixed findings (Jesus-Ribeiro et al., 2017; Gallagher et al., 2010; Skorvanek et al., 2015; Luo et al., 2005; Martínez-Martín et al., 2005). Two studies reported a significant relationship between stigma and the experience of pain (Gallagher et al., 2010; Jesus-Ribeiro et al., 2017). Both studies suggest that greater levels of pain are associated with higher reports of personal experience of stigma. However, three studies report a non-significant relationship between stigma and pain (Skorvanek et al., 2015; Luo et al., 2005; Martínez-Martín et al., 2005).

Sleep and Fatigue

Four of the reviewed studies examined the relationship between stigma and sleep/fatigue (Martínez-Martín et

al., 2005; Skorvanek et al., 2015; Tu et al., 2017; Gallagher et al., 2010). Three studies report a non-significant relationship between these factors (Martínez-Martín et al., 2005; Skorvanek et al., 2015; Tu et al., 2017). Gallagher et al. (2010) report a significant relationship between stigma and sleep/fatigue. When compared with Gallagher et al. (2010) the overall quality of the studies that report a non-significant relationship was higher. Thus, at present, there appears to be no relationship between stigma and sleep/fatigue.

In summary, stigma appears to be correlated with activities of daily living, with higher reports of stigma associated with reduced activities of daily living. Mixed findings are present for the relationship between stigma and pain. There appears to be no clear evidence of a relationship between stigma and fatigue, and stigma and

sleep. There is growing evidence to suggest that stigma is a predictor of HRQoL.

Discussion

Key Findings

The findings of this review indicate that there is a complex relationship between stigma and demographic, illness, psychological and quality of life factors.

Two studies found a significant relationship between stigma and age, with younger individuals reporting higher levels of stigma (Carod-Artal et al., 2007; Skorvanek et al., 2015). The significant findings by Carod-Artal et al., (2007) and Skorvanek et al. (2015) may be understood from the perspective that younger individuals may experience higher levels of scrutiny by peers, and physical appearance may be considered of greater value compared to older aged individuals

(Tiggemann & Lynch, 2001). Younger individuals may have a greater feeling of pressure to appear similar to their social group in order to be accepted by others. This may reflect similarities with Goffman's work, as individuals wish to align themselves with particular social groups (Goffman, 1963). In addition, it may be that older aged individuals may have more coping strategies and are more resilient to the effects of stigma (Gooding, Hurst, Johnson & Tarrier, 2012). It has also been reported that with age, there is an expectation of physical health decline and this may be perceived as less disruptive to an individual's sense of self (Bury, 1982; Faircloth, Boylestein, Rittman, Young & Burium, 2004). However, the effect of condition severity over time as the illness progresses may be conflating the relationship between age and stigma. In contrast, two papers have reported a non-significant relationship

between stigma and age (Simpson et al., 2014; Zhao et al., 2008). Therefore, it remains unclear if a relationship exists given that only two studies found this effect. It could be argued that studies with higher methodological rigor found no effect, thus from two studies alone, there appears to be no strong evidence of a relationship between stigma and age. This may also reflect a decline in stigma experience for individuals beyond the age of 65, due to expectations of illness with increasing age.

From the studies which examined the relationship between stigma and condition severity (Skorvanek et al., 2015; Gallaher et al., 2010), it appears that the experience of stigma may be associated with physiological decline. These results support Goffman's views on visible difference leading to an increase in stigmatisation (Goffman et al., 1963). The findings also

support the notion of visibility identified by Jones (1984) which suggests that as the course of the condition develops, the effects may be more visible to others which increases the risk of stigma. Equally, an individual experiencing the condition may become more aware of the extent of its visibility and perceive themselves to be stigmatised. With progressive illness an individual's physical functioning may decrease and this may impact upon their perception of; control (MacCarthy & Brown, 1989), self-worth (Baker & Graham, 2004) and stigma (Ma et al., 2016).

When examining the relationship between stigma and psychological factors, the weight of findings appears to suggest that stigma is associated with higher depression (10 studies) and higher anxiety (7 studies). Increasing symptoms of condition severity is associated with feeling

less valued (Scambler, 1989) and a reduction in the perception of capabilities (De Ridder, Geenen, Kuijer, & van Middendorp, 2008) and self-efficacy (Marks & Allevante, 2005). Low self-efficacy is associated with depression (Soysa & Wilcomb, 2015). Furthermore, experiencing increasing symptoms may serve to disrupt the dynamic of social interactions or lead to individuals isolating themselves, which again may lead to depression (Jones, 1984; Hermanns, 2013). With increasing symptoms, the aesthetic quality of the condition becomes more visible. This may hinder social interactions further. While depression may be a consequence of stigma, it may also in turn increase stigma perceptions. Individuals who experience depression can perceive situations more negatively, thus, may report more experiences of stigma (Gotlib, 1983). The direction of this relationship is currently

unknown and further research is required to determine if a uni or bi-directional relationship exists between these variables.

A number of studies found a relationship between stigma and factors associated with HRQoL, such as activities of daily living. The results in this area suggest that higher levels of stigma are associated with reduced perceptions of daily functioning. Stigma may influence an individual's ability to take part in everyday or social functions (Jesus-Ribeiro et al, 2017). This may be due to individuals' concerns or experiences of appearing different to others in society (Goffman; 1963). An individual who has increased symptoms of PD may be at greater risk of experiencing stigma and as a result may have restricted social functioning. Jones' (1984) account of concealment may provide some explanation of the

relationship between stigma and activities of daily living, including social functioning. Individuals may become more aware of the condition due to its visibility and again this may result in stigma which could lead to an individual isolating themselves or reducing their activities (Hermanns, 2013). Life satisfaction is often obtained through participation and enjoyed activities. For individuals who experience chronic and progressive conditions, where participation is more challenging or no longer possible, this is likely to affect self-perception (De Ridder et al., 2008). Thus, with time, individuals may participate less (Thordardottir, Nilsson, Iwarsson, & Haak, 2014).

Link and Phelan's (2001) stigma definition suggests, that stigma occurs in societies that allow processes of labelling, stereotyping and devaluing to occur. This may

explain the importance of geography and culture for the stigma experience (Klepac et al., 2007; Hechtner et al., 2014). Given that the effect of country and culture was not examined in other studies in this review, replications are required before further conclusions can be drawn.

There are contrasting results reported in a number of studies that examined aspects of HRQoL, such as the relationship between stigma and pain, and stigma and sleep/fatigue. Direct comparison of the papers' findings is challenging due to the varied scales adopted in each study. Therefore, further replication of studies is required before conclusions can be drawn. The underlying relationship between stigma and aspects of HRQoL for individuals with neurodegenerative conditions concerned in this review remains unclear.

Stigma and the significantly associated factors of condition severity, psychological wellbeing and HRQoL, may impact each other in a bidirectional relationship.

Further research is required to determine the direction of these associations using more powerful statistical techniques.

Implications and recommendations

The weight of evidence in this review points to a relationship between higher stigma and increased psychological distress, particularly in the form of anxiety and depression. Therefore, it may be necessary for interventions to target both sides of this relationship at a community and an individual level (reducing both stigma and psychological difficulties). For health professionals this may take the form of awareness raising and information sharing about the condition and its effects on

the individual and wider systems. Developing a greater public understanding may help to reduce any concerns or misconceptions surrounding the condition which may also serve to diminish stigmatisation.

Experiences of stigma may result in an individual feeling worthless, less valued by others and may be associated with symptoms of depression (Carod-Artal et al., 2008).

Therefore, it is important for individuals with these conditions to feel included and valued as an individual and not defined by their condition.

To assist with inclusion beyond the context of family and health care settings, it is the responsibility of health care professionals to increase societal awareness of these conditions. This may be achieved through the effective use of advertising campaigns across a broad spectrum of media formats, from written documents to social

media platforms. This would target a wide range of individuals and increase societal understanding of neurodegenerative conditions (Parkinson's UK). For example, raising public awareness has been shown to reduce stigmatisation for individuals who experience Alzheimer's dementia (Devlin, MacAskill, & Stead, 2007).

In addition, specific psychological interventions may be appropriate for individuals with these neurodegenerative conditions to reduce anxiety and depression. For example, acceptance and commitment therapy (ACT; Hayes, Strosahl, & Wilson, 1999) promotes acceptance and the pursuit of action in line with an individual's values. This approach has been shown to increase psychological flexibility, decrease self-stigma (Luoma, & Platt, 2015) and reduce anxiety and depression

(Forman, Herbert, Moitra, Yeomans, & Geller, 2007).

Cognitive fusion has been found to mediate the relationship between stigma and emotional wellbeing (including anxiety, depression and HRQoL; Valvano et al., 2016). Depression and anxiety were also found to mediate the relationship between stigma and cognitive fusion (Valvano et al., 2016). ACT directly targets cognitive fusion to promote increased flexibility of thought, thereby having the potential to reduce the detrimental effect of stigma on psychological wellbeing. Utilising a narrative approach, self-advocacy and group therapy (White & Epston, 1990), helps individuals to 'thicken' their identity in a strengths-based manner. This may help individuals to take notice of their own value and see themselves as more than just their condition.

Compassion focused therapy (CFT; Gilbert, 2009) has also been efficacious in reducing the effect of health-related stigma (Luoma & Platt, 2015). It has been shown that developing compassion towards the self, may act as a coping resource which individuals could utilize in the event of a distressing experience (Terry & Leary, 2011). Cultivating compassion can reduce anxiety (Gilbert & Procter, 2006) and depression (Diedrich, Grant, Hofmann, Hiller, & Berking, 2014).

Review strengths and limitations

Within this review attempts were made to maximise the search strategy and ensure relevant results were captured. Considering these neurodegenerative conditions together in terms of their visible motor difficulties enables inferences to be developed using a larger evidence base. However, as the search did not

identify any results relevant to the conditions of MND/ALS and HD, future studies that focus on these conditions are required.

Furthermore, all studies were cross-sectional in design, therefore longitudinal studies are also required to establish if relationships change over the life course.

The data examined in this review illustrates the relationship between two variables; however, neither direction nor causality can be inferred. Further research is required which examines the relationships using more statistically powerful techniques to further our understanding of direction of relationships.

Across the twenty studies, five different measures were used to assess stigma. All measures for stigma were self-report. The stigma scales varied in length, ranging from one item to twenty-two items, and clearly the

shorter scales could not capture the complexity of the construct. Furthermore, none of the scales differentiated between perceived and enacted stigma; thus, our understanding is limited of how different aspects of stigma may be related to psychological wellbeing. It may be useful for further research to concentrate on the development of more sensitive scales which are able to identify the subtleties of stigma in relation to its component parts. For example, the Stigma Scale for Chronic Illnesses (SSCI) is well-validated for use with individuals who have neurodegenerative conditions (Molina, Choi, Cella & Rao, 2013) and is able to distinguish between perceived versus enacted stigma (Rao, et al., 2009). Moreover, this information will assist with appropriate and potentially more cost-effective intervention development. For example, if sensitive stigma measures indicate that enacted stigma is

important for wellbeing, then interventions at a systemic and societal level may be most appropriate. Further to this, the study by Airlie et al. (2001) used a stigma scale which was developed for use with individuals with epilepsy (Tedman et al., 1995). The scale was used for a sample of individuals with MS, however there was no justification for this and the authors gave no indication that the scale had been validated with this population. In addition, when examining the scale, the language used appeared to be culturally specific, utilising idioms and expressions which may not be familiar to a contemporary, cross-culturally diverse sample (Nordmann & Jambazova, 2017). It is therefore useful to consider how scales are developed and used within a cultural and condition-specific context. Self-report measures are culturally sensitive, with individuals from Western and non-Western backgrounds showing

differences in the degree to which they can hold both positive and negative beliefs regarding a particular concept (Spencer-Rodgers, Peng, Wang & Hou 2004). Given that little information was reported on the background of individuals who took part in the studies, greater demographic detail would help to examine the cultural differences with stigma experience.

Conclusion

This review aimed to examine the relationship between stigma and demographic, social and clinical factors for individuals with specific neurodegenerative conditions. The findings indicate that stigma is related to condition severity, psychological factors and perceptions of HRQoL. Future research should statistically examine the relationships between stigma and demographic, social and clinical variables using more complex models

to determine if bidirectional relationships exist. By furthering our understanding of the relationships between stigma and these variables, clinical practice can be enhanced at an individual and community level.

Policies and campaigns should aim to increase awareness and understanding of these neurodegenerative conditions in order to acknowledge difference and promote inclusion.

Health professionals and third sector organisations have a responsibility to educate and raise awareness on the nature and impact of these conditions. Locating change at a societal level may help towards preventing stigmatising experiences for individuals with neurodegenerative conditions.

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Appendix A. Quality appraisal checklist

Checklist

This checklist has been developed for assessing the validity of studies reporting correlations. It is based on the appraisal step of the 'Graphical appraisal tool for epidemiological studies (GATE)', developed by Jackson et al. (2006).

This checklist enables a reviewer to appraise a study's internal and external validity after addressing the following key aspects of study design: characteristics of study participants; definition of independent variables; outcomes assessed and methods of analyses.

There are 5 sections of the revised GATE. Section 1 seeks to assess the key population criteria for determining the study's EXTERNAL VALIDITY – that is, the extent to which the findings of a study are generalisable beyond the confines of the study to the study's source population.

Sections 2 to 4 assess the key criteria for determining the study's INTERNAL VALIDITY – that is, making sure that the study has been carried out carefully, and that the identified associations are valid and are not due to some other (often unidentified) factor.

Checklist items are worded so that 1 of 5 responses is possible:

++	Indicates that for that particular aspect of study design, the study has been designed or conducted in such a way as to minimise the risk of bias.
+	Indicates that either the answer to the checklist question is not clear from the way the study is reported, or that the study may not have addressed all potential sources of bias for that particular aspect of study design.
–	Should be reserved for those aspects of the study design in which significant sources of bias may persist.
NOT REPORTED (NR)	Should be reserved for those aspects in which the study under review fails to report how they have (or might have) been considered.

NOT APPLICABLE (NA)	Should be reserved for those study design aspects that are not applicable given the study design under review (for example, allocation concealment would not be applicable for case–control studies).
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In addition, the reviewer is requested to complete in detail the comments section of the quality appraisal form so that the grade awarded for each study aspect is as transparent as possible.

Each study is then awarded an overall study quality grading for internal validity (IV) and a separate one for external validity (EV):

- ++ All or most of the checklist criteria have been fulfilled, where they have not been fulfilled the conclusions are very unlikely to alter.

- + Some of the checklist criteria have been fulfilled, where they have not been fulfilled, or not adequately described, the conclusions are unlikely to alter.
- – Few or no checklist criteria have been fulfilled and the conclusions are likely or very likely to alter.

Checklist

STUDY IDENTIFICATION: Include full citation details
STUDY DESIGN: Refer to the glossary of study designs (<u>appendix D</u>) and the algorithm for classifying experimental and observational study designs (<u>appendix E</u>) to best describe the paper's underpinning study design
GUIDANCE TOPIC:

ASSESSED BY:		
SECTION 1: POPULATION		
<p>1.1 IS THE SOURCE POPULATION OR SOURCE AREA WELL DESCRIBED?</p> <ul style="list-style-type: none"> Was the country (e.g. developed or non-developed, type of health care system), setting (primary schools, community centres etc), location (urban, rural), population demographics etc adequately described? 	<p>++ + - NR NA</p>	<p>Comments:</p>
<p>1.2 IS THE ELIGIBLE POPULATION OR AREA REPRESENTATIVE OF THE SOURCE POPULATION OR AREA?</p>	<p>++ + - NR</p>	<p>Comments:</p>

<ul style="list-style-type: none"> • Was the recruitment of individuals, clusters or areas well defined (e.g. advertisement, birth register)? • Was the eligible population representative of the source? Were important groups underrepresented? 	NA	
<p>1.3 DO THE SELECTED PARTICIPANTS OR AREAS REPRESENT THE ELIGIBLE POPULATION OR AREA?</p> <ul style="list-style-type: none"> • Was the method of selection of participants from the eligible population well described? • What % of selected individuals or clusters agreed to participate? Were there any sources of bias? • Were the inclusion or exclusion criteria explicit and appropriate? 	++ + - NR NA	Comments:

SECTION 2: METHOD OF SELECTION OF EXPOSURE (OR COMPARISON) GROUP		
<p>2.1 SELECTION OF EXPOSURE (AND COMPARISON) GROUP. HOW WAS SELECTION BIAS MINIMISED?</p> <ul style="list-style-type: none"> How was selection bias minimised? 	<p>++ + - NR NA</p>	<p>Comments:</p>
<p>2.2 WAS THE SELECTION OF EXPLANATORY VARIABLES BASED ON A SOUND THEORETICAL BASIS?</p> <ul style="list-style-type: none"> How sound was the theoretical basis for selecting the explanatory variables? 	<p>++ + - NR NA</p>	<p>Comments:</p>

<p>2.3 WAS THE CONTAMINATION ACCEPTABLY LOW?</p> <ul style="list-style-type: none"> • Did any in the comparison group receive the exposure? • If so, was it sufficient to cause important bias? 	<p>++ + – NR NA</p>	<p>Comments:</p>
<p>2.4 HOW WELL WERE LIKELY CONFOUNDING FACTORS IDENTIFIED AND CONTROLLED?</p> <ul style="list-style-type: none"> • Were there likely to be other confounding factors not considered or appropriately adjusted for? • Was this sufficient to cause important bias? 	<p>++ + – NR NA</p>	<p>Comments:</p>
<p>2.5 IS THE SETTING APPLICABLE TO THE UK?</p> <ul style="list-style-type: none"> • Did the setting differ significantly from the UK? 	<p>++ +</p>	<p>Comments:</p>

	– NR NA	
SECTION 3: OUTCOMES		
<p>3.1 WERE THE OUTCOME MEASURES AND PROCEDURES RELIABLE?</p> <ul style="list-style-type: none"> • Were outcome measures subjective or objective (e.g. biochemically validated nicotine levels ++ vs self-reported smoking –)? • How reliable were outcome measures (e.g. inter- or intra-rater reliability scores)? • Was there any indication that measures had been validated (e.g. validated against a gold standard measure or assessed for content validity)? 	++ + – NR NA	Comments:

<p>3.2 WERE THE OUTCOME MEASUREMENTS COMPLETE?</p> <ul style="list-style-type: none"> • Were all or most of the study participants who met the defined study outcome definitions likely to have been identified? 	<p>++ + – NR NA</p>	<p>Comments:</p>
<p>3.3 WERE ALL THE IMPORTANT OUTCOMES ASSESSED?</p> <ul style="list-style-type: none"> • Were all the important benefits and harms assessed? • Was it possible to determine the overall balance of benefits and harms of the intervention versus comparison? 	<p>++ + – NR NA</p>	<p>Comments:</p>
<p>3.4 WAS THERE A SIMILAR FOLLOW-UP TIME IN EXPOSURE AND COMPARISON GROUPS?</p>	<p>++ +</p>	<p>Comments:</p>

<ul style="list-style-type: none"> • If groups are followed for different lengths of time, then more events are likely to occur in the group followed-up for longer distorting the comparison. • Analyses can be adjusted to allow for differences in length of follow-up (e.g. using person-years). 	– NR NA	
3.5 WAS FOLLOW-UP TIME MEANINGFUL? <ul style="list-style-type: none"> • Was follow-up long enough to assess long-term benefits and harms? • Was it too long, e.g. participants lost to follow-up? 	++ + – NR NA	Comments:
SECTION 4: ANALYSES		

<p>4.1 WAS THE STUDY SUFFICIENTLY POWERED TO DETECT AN INTERVENTION EFFECT (IF ONE EXISTS)?</p> <ul style="list-style-type: none"> • A power of 0.8 (i.e. it is likely to see an effect of a given size if one exists, 80% of the time) is the conventionally accepted standard. • Is a power calculation presented? If not, what is the expected effect size? Is the sample size adequate? 	<p>++ + – NR NA</p>	<p>Comments:</p>
<p>4.2 WERE MULTIPLE EXPLANATORY VARIABLES CONSIDERED IN THE ANALYSES?</p> <ul style="list-style-type: none"> • Were there sufficient explanatory variables considered in the analysis? 	<p>++ + – NR NA</p>	<p>Comments:</p>

<p>4.3 WERE THE ANALYTICAL METHODS APPROPRIATE?</p> <ul style="list-style-type: none"> • Were important differences in follow-up time and likely confounders adjusted for? 	<p>++ + – NR NA</p>	<p>Comments:</p>
<p>4.6 WAS THE PRECISION OF ASSOCIATION GIVEN OR CALCULABLE? IS ASSOCIATION MEANINGFUL?</p> <ul style="list-style-type: none"> • Were confidence intervals or p values for effect estimates given or possible to calculate? • Were CIs wide or were they sufficiently precise to aid decision-making? If precision is lacking, is this because the study is under-powered? 	<p>++ + – NR NA</p>	<p>Comments:</p>
<p>SECTION 5: SUMMARY</p>		

<p>5.1 ARE THE STUDY RESULTS INTERNALLY VALID (I.E. UNBIASED)?</p> <ul style="list-style-type: none"> • How well did the study minimise sources of bias (i.e. adjusting for potential confounders)? • Were there significant flaws in the study design? 	<p>++ + –</p>	<p>Comments:</p>
<p>5.2 ARE THE FINDINGS GENERALISABLE TO THE SOURCE POPULATION (I.E. EXTERNALLY VALID)?</p> <ul style="list-style-type: none"> • Are there sufficient details given about the study to determine if the findings are generalisable to the source population? • Consider: participants, interventions and comparisons, outcomes, resource and policy implications. 	<p>++ + –</p>	<p>Comments:</p>

Section Two: Research paper

**Does perceived control mediate the relationship
between stigma and wellbeing for individuals with
Parkinson's disease?**

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Abstract

Objective

The purpose of this study was to investigate whether the perception of control mediates the relationship between stigma and wellbeing in people with Parkinson's disease.

Design

A survey of quantitative, cross-sectional design was used. Data were analysed using mediation regression analyses.

Method

Adults with Parkinson's disease were invited to take part in a survey online, or by paper on request.

Two hundred and twenty-nine individuals completed quantitative measures of stigma and perceived control, and a full exploration of the concept of wellbeing

(including health-related quality of life, depression, anxiety, stress and positive affect).

Results

Mediational regression analyses indicated that the perception of control mediated the relationship between stigma and a number of factors: health-related quality of life, depression and positive affect. Perceived control did not, however, mediate the relationship between stigma and anxiety nor between stigma and stress.

Conclusion

These findings suggest that in people with Parkinson's disease, perceived control may play an important role in explaining the relationship between stigma and some aspects of wellbeing. Perceived control should be considered within clinical and everyday environmental settings, to target the relationship between stigma and

wellbeing, for individuals with Parkinson's disease.

Interventions which focus on increasing perceived control (e.g. cognitive behaviour therapy), and how these may affect stigma and wellbeing are outlined.

Keywords: Stigma, perceived control, HRQoL, wellbeing, neurodegenerative, Parkinson's disease, anxiety, depression, stress, positive affect.

Parkinson's disease is a neurodegenerative condition affecting 27 in every 10,000 individuals in the UK (Parkinson's UK, 2009), and one percent of those over 60 years of age internationally (Dorsey et al., 2007; Hirtz et al., 2007). Individuals are likely to experience tremor, rigidity and slowness of movement, as the primary motor problems (Jankovic, 2008). Individuals may also have cognitive, sleep and psychological difficulties (Menza & Marsh, 2006). These experiences – including both those

more directly disease-related and those associated with living with such a condition - can result in visible difference, and difference within society can be associated with stigma (Jones et al., 1984).

Classic accounts of stigma suggest it occurs in response to characteristics that deviate from the social norm and are considered to be of less value (e.g., Goffman, 1963). Stigma can involve direct acts from others (e.g. being called derogatory names, or being stared at), and may be felt by an individual with PD as a result of internalising negative societal stereotypes (Scambler, 1989).

Stigma has been shown to be related to a range of negative outcomes including reduced social support, occupational loss and social exclusion (Goffman, 1963; Weiner, Perry & Magnusson, 1988). Stigma is also

associated with increased reports of shame, embarrassment and poor self-esteem in general research (Link & Phelan, 2001; Rao et al., 2009) and in people with PD (Maffoni, Giardini, Pierobon, Ferrazzoli & Frazzitta, 2017; Schrag, Jahanshah & Quinn, 2001).

The relationship between stigma and psychological wellbeing is complex. For some individuals with Parkinson's, there appears to be an association between stigma experiences and high anxiety and depression (Carod-Artal et al., 2008; Jesus-Ribeiro, Vieira, Ferreira, Januário & Freire, 2017; Luo et al., 2005; Simpson, Lekwuwa, & Crawford, 2014). For others, the experience of stigma does not appear to correlate with some indicators of wellbeing e.g. anxiety and depression (Skorvanek et al., 2015) and positive affect (Simpson et al., 2014). Therefore, there may be

other factors that influence the effect of stigma on indices of wellbeing.

One variable which might explain the differing effects on stigma on measures associated with well-being is perceived control, understood as the level of control felt by an individual generally (i.e. over their life) or, as is more usual in health psychology, in health-related contexts. Control as a concept has been extensively used as both a predictor and outcome measure in health psychology (e.g. Eccles & Simpson, 2011), is included in a number of theoretical models (e.g. self-regulatory model: Leventhal, Leventhal & Cameron, 2001) and has been shown to predict well-being, with higher levels of control generally (although with some important caveats) predicting higher levels of well-being. Interestingly, the theoretical construct has also been identified by Parkinson's UK members, in response to a general

survey, as important to wellbeing (Parkinson's UK, 2015). For individuals with chronic health conditions, high levels of perceived control are generally associated with high scores of health-related quality of life (HRQoL) and low levels of anxiety, depression and negative affect (Hagger & Orbell, 2003; Leventhal, Nerenz & Steele, 1984).

Obtaining a sense of perceived control over PD is challenging due to the chronic, unpredictable and degenerative nature of the condition. However, it is possible for individuals with PD to gain a sense of control over other aspects of their lives (Eccles & Simpson, 2011; Eccles, Murray & Simpson, 2011) or different aspects of their condition (e.g. asking for medication reviews).

Given the significance of perceived control for individuals with PD, it could be hypothesised that perceived control underpins the relationship between stigma and wellbeing and so acts as an important mediating variable. The aim of this study was to test this theoretical assumption via a mediation analysis. It is accepted that wellbeing is a well-used term with no fixed and agreed definition (e.g. Ryff & Keyes, 1995).

Wellbeing in this study was characterised by both the absence of mental health difficulties (i.e. as measured by depression and anxiety scales) and by the presence of positive affect. It also included a measure of health-related quality of life (HRQoL). HRQoL is a multi-dimensional concept which provides a more holistic account of individuals' levels of satisfaction over a number of life domains (Fallowfield, 1990). Two measures of perceived control were incorporated (a

general/non-health specific measure, and a Parkinson's disease specific measure). Both these measures were used in order to assess whether control operated at a generic level or in relation to the specifics of living with Parkinson's.

Consequently, as has been outlined above, the model being tested is that perceived control mediates the relationship between stigma and measures of wellbeing. While of theoretical interest, this model would also have implications relevant to clinical psychology both in individual formulations and in in relation to societal impact (see also Simpson, McMillan & Reeve, 2013).

It is hypothesised from the research reviewed that high levels of stigma would be associated with high levels of anxiety, depression, stress and reduced HRQoL and positive affect. It was also hypothesised, again based on

previous research, that perceived control (on both scales) would positively correlate with HRQoL and positive affect and negatively correlate with depression, anxiety and stress. It is therefore hypothesised that perceived control may play a mediating role in the relationship between the assumed predictor (stigma) and each aspect of wellbeing measured.

Method

Design

The study was a cross-sectional survey comprised of quantitative measures. The data were examined using mediation analysis. Mediation analysis was conducted using Hayes PROCESS tool (Hayes, 2013) to examine whether perceived control mediated the relationship between stigma and wellbeing. Figure 1 shows a path diagram for the analyses.

Inclusion criteria

- Individuals who self-reported a diagnosis of PD
- Individuals who were 18 years or above
- The survey as written in English, thus, participants required sufficient knowledge of written English to take part
- Participants were able to complete the survey measures either alone or with support.

Participants

All participants were recruited from a large UK-based PD charity (Parkinson's UK). The study was advertised online by the charity from September 2017 to December 2017. Individuals who met the inclusion criteria were eligible to participate in the study (see inclusion criteria).

Two hundred and fifty individuals participated in the survey. Twenty participants were removed due to large

amounts of missing data (twelve provided only demographic information, two missed one measure and six missed more than one measure). A Kolmogorov-Smirnov (K-S) test was not conducted, due to the large sample size in this study, as samples larger than 100 participants lead to an increase in the chance of Type I error (Field, 2013). Thus, normality of the data was assessed by visual inspection, using histograms and boxplots. These indicated one extreme data point which was removed from the dataset. The remaining dataset consisted of 229 participants. Methods of mean imputation and pro-rating of individual cases was used for 14 participants due to small amounts of missing data, e.g. individual items missing (Field, 2013).

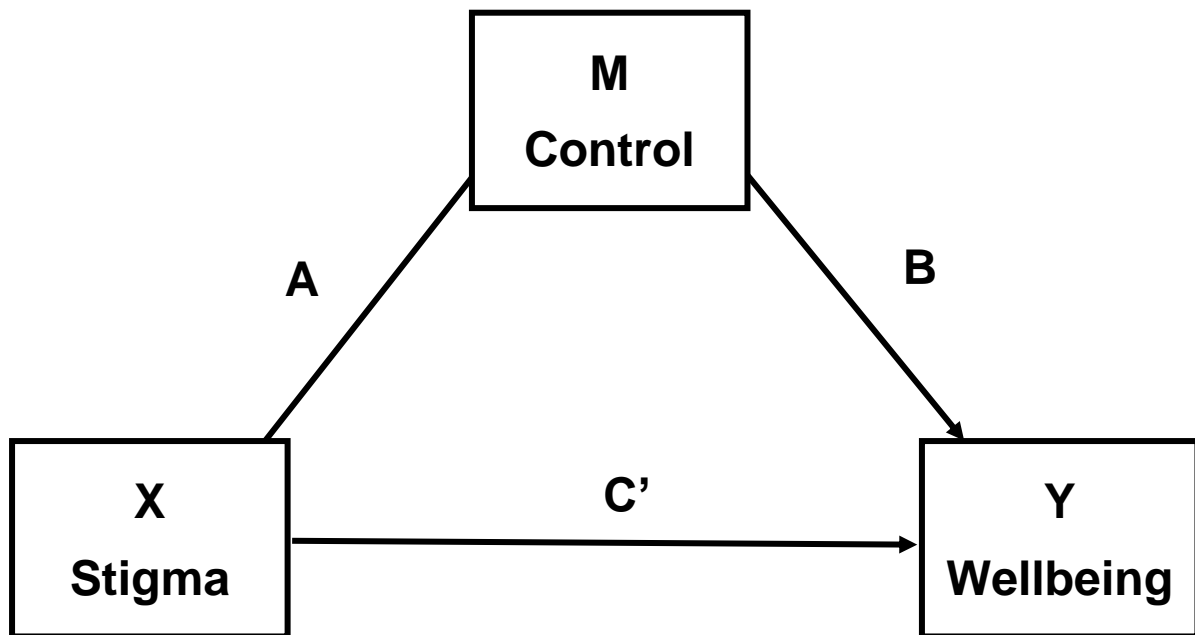


Figure 1. Path diagram.

Parameters A, B and C' denote path (regression) coefficients.

Materials

The survey included demographic and clinical questions alongside validated measures.

The demographic variables collected were; age, gender, ethnicity, work status, relationship status and living arrangements (alone, co-habiting, residential/nursing

home). The clinical variables collected were; age of symptom onset, age of diagnosis and whether taking medication.

Validated Measures

Predictor Variable

The Stigma Scale for Chronic Illness (SSCI; Rao et al., 2009) measures both perceived and enacted stigma and has been validated for use with individuals with neurological conditions such as PD (Molina, Choi, Cella & Rao, 2013). This 24-item scale was developed to gather information about individuals' feelings towards their experience of having a neurological condition. The scale consists of 2 subscales; perceived stigma and enacted stigma. The perceived stigma subscale contains 13 questions about an individual's feelings regarding their condition, focusing on any worries or feelings of embarrassment. Answers are given on a 5-

point Likert scale from 1 = never, to 5 = always, with scores ranging from 13 to 65. The enacted subscale consists of 11 items with scores range between 11 and 55. Questions relate to an individuals' objective experience of stigma such as noticing people staring. Scores on the two subscales are summed to create a total stigma score. Higher scores indicate higher experiences of stigma. The scale is reported to have good content and internal validity (Stevelink, Wu, Voorend & van Brakel, 2012), and good internal consistency with a Cronbach's alpha of 0.92 (Anagnostouli et al., 2016).

Mediator Variables

The Parkinson's UK Scale of Perceived Control (PUKSoPC) was developed with Parkinson's UK members and has been comprehensively validated (Simpson, Chatzidamianos, Fletcher, Perpetuo, &

Eccles, 2018). The scale consists of 15 items with five subscales: Think positive, Get informed, Do things, Make plans, and Be involved, rated on a 5-point Likert scale. There are three questions within each subscale that are summed, with the total score for subscales ranging from 3 to 15. Subscales can also be summed to form an overall score for the scale, which may range from 15 to 75. Higher scores indicate greater perceived control. The internal consistency for the overall score of the scale has been reported at .92; along with the Cronbach's alpha for each of the subscales (Think positive: .87, Get informed: .77, Do things: .86, Make plans: .79, Be involved: .80; Simpson et al., 2018).

The General Self-Efficacy Scale (GSE; Jerusalem & Schwarzer, 1992) was used as a general/non-health specific measure of perceived control. It assesses individuals' general beliefs in their ability to respond to

and problem solve situations. The scale is unidimensional, consisting of 10 questions with response options on a 4-point Likert scale (1 = not at all true, to 4 = exactly true), with possible scores ranging from 10 to 40. The scale is a reliable and valid measure for use with individuals experiencing PD (Nilsson, Hagell & Iwarsson, 2015). Internal consistency of the scale has been reported at .76 to .90 across 23 nations (Schwarzer & Jerusalem, 1995).

Outcome Variables

The Parkinson's Disease Questionnaire (PDQ) was used to measure health-related quality of life (Jenkinson et al., 2012). This is a short form consisting of 8 items which have been taken from a larger 39-item measure (PDQ-39; Jenkinson et al., 1998). The short form consists of items measuring mobility, activities of daily living, emotional wellbeing, social support, cognitions,

communication, bodily discomfort and stigma.

Respondents are asked to rate items for how frequently they experience difficulty in that domain. Items are rated on a 5-point Likert scale (1 = Never, to 5 = Always/Cannot do at all), with total scores ranging from 8-40. Lower scores indicate higher HRQoL, while higher scores indicate the reverse. This scale has been found to be a valid and reliable measure which can be used cross-culturally (Jenkinson & Fitzpatrick, 2007), with an internal consistency of .74.

The Depression Anxiety and Stress Scale-21 (DASS-21; Lovibond & Lovibond, 1995) is a well-validated short-form version of the original scale (Henry & Crawford, 2005) and has been used with the PD population (Birtwell, Dubrow-Marshall, Dubrow-Marshall, Duerden, & Dunn, 2017). The short-version is considered to be more acceptable to individuals completing the measure

(Henry & Crawford, 2005). The measure consists of three subscales: depression, anxiety, and stress.

Subscales include 7 items and individuals indicate on a 4-point Likert scale whether items have been relevant to them in the past few weeks (response options range from 0 = does not apply, to 3 = applies very much/most of the time). Total scores range from 0-63, with higher scores indicating more severe depression, anxiety or stress. The internal consistency for the DASS total score has been reported at .93, and for each of the subscales: depression at .88, anxiety at .82, and stress at .90 (Henry & Crawford, 2005).

The positive subscale of the Positive and Negative Affect Schedule (PANAS; Watson, Clark & Tellegen, 1988) was used to measure positive affect in PD in the last few weeks. Only the 10-item positive subscale was administered as, the DASS already provided an

assessment of negative mood. The measure is rated on a 5-point Likert scale (1 = very slightly or not at all, 5 = extremely), with total scores ranging from 10-50. Higher scores represent higher levels of positive affect. The PANAS is a reliable and valid measure of positive affect in non-clinical populations (Crawford & Henry, 2004) and has been used in people with Parkinson's (Simpson, Lekwuwa & Crawford, 2013). Internal consistency (Cronbach's alpha) was reported for the positive subscale at .86-.90 (Watson, Clark & Tellegen, 1988).

All measures were formatted to facilitate online use.

Procedure

Parkinson's UK advertised the study to members of the charity on their website. After reading the advertisement, participants could select an option to find out further information where they were redirected to a page hosted

by Qualtrics (2013) regarding the study. Participants then read an information sheet about the study and consented to take part in the research. When consent had been given, the online survey was made available (see Section 4 for survey). Participants were given the option to complete a paper survey. Two individuals requested paper copies, which were sent directly to be returned free of charge. The survey took approximately 30 minutes to complete. Data from paper versions were inputted into Qualtrics (by the researcher). Data were downloaded from Qualtrics site to create an electronic dataset.

Data analysis

The study was powered to find a medium effect size for both the relationship between stigma and perceived control, and the relationship between perceived control and wellbeing within the mediation. A minimum number

of 71 participants were required to provide a sufficiently powered study of .8, with a significance value of $p < .05$ (Fritz & MacKinnon, 2007).

The data were assessed for normality to ensure that no extreme data points would influence the model. The data were then analysed using inferential statistics.

Pearson's r correlations were conducted to determine the relationship of the predictor, demographic or clinical variables to the outcome variables.

Mediational regression analyses were conducted to determine if the perception of control mediated the relationships between stigma and wellbeing.

Inferential analysis

Pearson's correlation coefficients were conducted between each outcome variable and demographic/psychosocial variables. The data were

then statistically examined using a mediational regression and only significant correlations ($p < .05$) were entered into the model (Field, 2013). Hayes PROCESS tool (Hayes, 2013), which implements a bias-corrected bootstrap model, was utilised to conduct the mediation regression. A bootstrap sample (of 1000 replications) was used in the analyses. Utilising bootstrapping techniques allows powerful statistical analyses to be conducted without having to meet the requirements of normality assumptions (Efron, 1987).

Results

Table 1 provides details of the demographics of the sample.

Table 1. Descriptive Statistics of the sample

	Value	Range
Age: mean (SD)		
Age in years	65 (8.00)	29-90
Age of symptom onset	57 (9.74)	26-90
Age of diagnosis	60 (9.32)	29-90
Gender: n (%)		
Female	116 (51)	-
Male	113 (49)	-
Ethnic group: n (%)		
White	227 (91)	-
Asian	2 (9)	-
Partnership status: n (%)		
Single	18 (8)	-
Married	191 (83)	-
Divorced	10 (4)	-
Widowed	10 (4)	-
Living arrangements: n (%)		
Alone	37 (16)	-

With others (partners, family and friends)	190 (83)	-
Residential/nursing home	1 (0.5)	-
Other	1 (0.5)	-
Work Status:		
Employed	42	-
Other (including retired)	187	-

Note: Percentages are rounded to the nearest whole number, except for percentages less than one, which are rounded to the nearest 0.5%. SD: standard deviation.

From the 229 participants who took part in the study, the mean age of the sample was 65 years (with a range of 44-93 years). Of the sample, 113 participants reported their gender as male, and 116 as female. Two hundred and twenty-seven individuals identified themselves as white, with 2 reporting being from an Asian background.

Of the 42 participants who identified as employed, 41 individuals provided information on their hours worked. This ranged from 10-70 hours per week. From the hours of work provided, 14 participants (34%) worked for 40 hours or more per week, 18 (44%) worked between 30-39 hours per week, 5 (12%) worked between 20-29 hours per week, and 4 (10%) worked between 10-19 hours per week.

Clinical characteristics of the sample

Of the individuals who reported age of symptom onset (n = 228), this ranged from 26-90 years. The majority of scores (71%) were between the ages of 50-69 years.

Of the participants who reported the age at which PD was diagnosed (n = 228), this ranged from 29-90 years. The majority of participants (72%) were diagnosed with PD between the ages of 50-69 years. 94% of

participants reported taking prescribed medication to manage the symptoms of PD.

Validated measures

See Table 2 for means, standard deviations (SD) and Cronbach's alpha of psychometric measures for the sample.

Table 2. Means, SDs and Cronbach's alpha of psychometric variables

Variable	M (SD)	Sample range	Cronbach's alpha
DASS-D	24.56 (10.13)	14-56	0.92
DASS-A	25.39 (7.78)	14-52	0.72
DASS-S	28.07 (9.51)	14-54	0.88
SSCI	50.13 (15.70)	24-103	0.94
PUKSoPC	56.53 (10.18)	23-75	0.89

PANAS	32.56 (9.27)	10-50	0.93
PDQ	17.96 (6.60)	8-37	0.85
GSE	29.42 (6.33)	10-40	0.94

Sample averages were interpreted using normative data and clinical cut off scores (Lovibond & Lovibond, 1995; Jenkinson & Fitzpatrick, 2007; Watson, Clark and Tellegen, 1988; Schwarzer, & Jerusalem, 1995; Simpson, Chatzidamianos, Fletcher, Perpetuo & Eccles, 2018; Molina, Choi, Cella & Rao, 2013). The mean of the sample indicated generally low levels for depression (in the mild range) which suggests that the sample were not experiencing difficulties with negative affect (Lovibond & Lovibond, 1995). The sample mean for anxiety fell within the higher range, indicating that the sample may have been experiencing moderately high

levels of anxiety (Lovibond & Lovibond, 1995). The sample mean for stress fell within the normal range, suggesting that on average the sample did not experience severe difficulties with stress (Lovibond & Lovibond, 1995). The mean of the sample for HRQoL was moderately low, indicating higher than average HRQoL (Jenkinson & Fitzpatrick, 2007). The mean score for PANAS was moderately high, indicating high levels of positive affect for the sample (Watson, Clark and Tellegen, 1988).

The sample reported generally high scores for GSE and PUKSoPC, which indicates high levels of perceived control (Schwarzer & Jerusalem, 1995; Simpson et al. 2018). The mean sample score for stigma was low, which suggests that the sample experienced low levels of stigma (Molina, Choi, Cella & Rao, 2013).

Overall, the scores indicate diverse experiences of stigma, perceived control and wellbeing. The sample means indicate that participants may have struggled with anxiety more than low mood or stress.

Inferential analyses

Correlational analyses

Prior to mediation regression, bivariate Pearson's correlations were carried out on the demographic and psychosocial variables (see Table 3a and 3b for details). All variables relating to the study's hypotheses (stigma, control and well-being) correlated in the directions hypothesised.

Table 3a. Correlates of demographic and validated measures

	SSCI	PUK- SoPC	GSE	PDQ	DASS-D	DASS-A	DASS-S	PANAS
Age	-.14*	.08	.02	.02	-.06	-.13	-.14*	.05
Gender	.11	.04	-.15*	-.02	-.02	.01	-.02	-.21
Work status	-.08	.20**	-.04	.05	-.04	-.08	-.01	.08
Relationship status	.11	-.14*	-.10	.12	.17*	.14*	.16*	-.13
Living status	-.07	.15*	.10	-.07	-.15*	-.11	-.13*	.13
Age of symptom onset	-.28**	.09	.12	-.14*	-.12	-.14*	-.14*	.09
Age of diagnosis	-.29**	.09	.13	-.14*	-.12	-.13	-.12	.09
Prescribed medication	-.10	.01	.10	-.11	-.05	-.04	-.01	.06

Note: *p value is less than .05. **p value is less than .01.

Table 3b. Correlations between validated measures

	SSCI	PUK- SoPC	GSE	PDQ	DASS-D	DASS-A	DASS-S	PANAS
SSCI	-	-.40**	-.40**	.69**	.60**	.46**	.53**	-.45**
PUKSoPC	-0.40**	-	.52**	-0.40**	-0.46**	-0.20	-0.28**	.66**
GSE	-0.39**	0.52**	-	-0.49**	-0.48**	-0.28**	-0.30**	0.69**

Note: *p value is less than .05. **p value is less than .01.

The SSCI correlated with all psychometric outcome measures (DASS; PDQ; PANAS) and both measures of perceived control (PUKSoPC; GSE). Significant correlations were found between the SSCI and DASS-D, DASS-A and DASS-S, indicating that higher experiences of stigma were associated with greater levels of depression, anxiety and stress. Significant negative correlations were found between the SSCI and PDQ, and the SSCI and PANAS, indicating that higher stigma scores were associated with lower quality of life and positive affect. Significant negative correlations were found between the SSCI and both measures of perceived control (PUKSoPC; GSE). This suggests that higher stigma scores were associated with lower scores of perceived control.

Significant relationships were found between both measures of perceived control (PUKSoPC; GSE) and all

psychometric outcomes variables. Significant negative correlations were found between both measures of perceived control (PUKSoPC; GSE) and DASS-D, DASS-A, and DASS-S, indicating that higher levels of perceived control were associated with lower levels of depression, anxiety and stress. Significant correlations were found between both measures of perceived control (PUKSoPC; GSE) and PDQ and PANAS, indicating that higher levels of perceived control are associated with increased HRQoL and positive affect.

A number of demographic variables correlated with outcome variables. Significant correlations were found between relationship status and depression and stress, and living arrangements and depression and stress; indicating that individuals not with a partner, or living alone, reported higher levels of depression and stress. Significant correlations were also found between age of

symptom onset and PDQ, and age of diagnosis and PDQ, indicating that individuals who experience symptoms at an older age, or who were diagnosed at an older age reported higher HRQoL. These demographic variables were consequently controlled within the regression models.

Regression analyses

Mediational regression analyses were performed and then re-examined while controlling for covariates. Tables 4-7 show the results of the adjusted and unadjusted mediation analyses.

Table 4. Mediation Models with PUK as mediator

	Model 1 X = stigma M = control Y = HRQoL	Model 2 X = stigma M = control Y = anxiety	Model 3 X = stigma M = control Y = depression	Model 4 X = stigma M = control Y = stress	Model 5 X = stigma M = control Y = positive affect
A					
b	-0.26**	-0.26**	-0.26**	-0.26**	-0.26**
CI	-0.34, -0.18	-0.34, -0.18	-0.34, -0.18	-0.34, -0.18	-0.34, -0.18
B					
b	-0.09*	-0.01	-0.26**	-0.08	0.52**
CI	-0.16, -0.03	-0.11, 0.09	-0.37, -0.15	-0.19, 0.03	0.43, 0.62
C'					
b	0.26**	0.23**	0.32**	0.30**	-0.13**
CI	0.22, 0.31	0.16, 0.29	0.25, 0.39	0.22, 0.37	0.19, 0.07
AB					
b	0.02	0.003	0.07	0.02	-0.14
CI	0.01, 0.05	-0.03, 0.03	0.03, 0.11	-0.01, 0.06	-0.19, -0.09

CSIE	0.06	-	0.11	-	-0.23
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Note: $A = (M \cdot X)$; $B = (M \cdot Y)$; C' = direct effect of X on Y, controlling for M; C = total effect of X on Y, not controlling for M; AB = proportion of effect that is mediated; b = mediated/indirect effect ($A \cdot B$); CI = confidence interval; CSIE: completely standardised indirect effect. * p value is less than .05. ** p value is less than .001.

Table 5. Mediation Models with PUK as mediator, with covariates

	Model 1 X = stigma M = control Y = HRQoL Covariates: Age of symptom onset; age of diagnosis	Model 2 X = stigma M = control Y = anxiety Covariates: Age of symptom onset; relationship status	Model 3 X = stigma M = control Y = depression Covariates: Relationship status; living status	Model 4 X = stigma M = control Y = stress Covariates: relationship status; living status
A				
b	-0.26**	-0.26**	-0.26**	-0.26**
CI	-0.35, -0.18	-0.34, -0.18	-0.34, -0.18	-0.33, -0.18
B				
b	-0.09*	-0.01	-0.25**	-0.07
CI	-0.16, -0.03	-0.10, 0.09	-0.36, -0.14	-0.18, 0.04
C'				
b	0.27**	0.22**	0.31**	0.29**
CI	0.23, 0.32	0.15, 0.29	0.24, 0.39	0.22, 0.37

AB				
b	0.25	0.01	0.06	0.02
CI	0.01, 0.05	-0.03, 0.03	0.03, 0.11	-0.02, 0.06
CSIE	0.06	-	0.10	-

Note: $A = (M \cdot X)$; $B = (M \cdot Y)$; C' = direct effect of X on Y, controlling for M; C = total effect of X on Y, not controlling for M; ab = proportion of effect that is mediated; b = mediated/indirect effect ($a \cdot b$); CI = confidence interval; CSIE: completely standardised indirect effect. * p value is less than .05. ** p value is less than .001.

Table 6. Mediation Models with GSE as mediator

	Model 1 X = stigma M = control Y = HRQoL	Model 2 X = stigma M = control Y = anxiety	Model 3 X = stigma M = control Y = depression	Model 4 X = stigma M = control Y = stress	Model 5 X = stigma M = control Y = positive affect
A					
B	-0.16**	-0.16**	-0.16**	-0.16**	-0.16**
CI	-0.21, -0.11	-0.21, -0.11	-0.21, -0.11	-0.21, -0.11	-0.21, -0.11
B					
B	-0.27**	-0.14	-0.46**	-0.17	0.89**
CI	-0.37, -0.17	-0.29, 0.02	-0.63, -0.29	-0.35, 0.01	0.74, 1.03
C'					
B	0.25**	0.21**	0.31**	0.29**	-0.12**
CI	0.21, 0.29	0.15, 0.27	0.24, 0.38	0.22, 0.36	-0.18, -0.07
AB					
B	0.04	0.01	0.07	0.02	-0.14
CI	0.02, 0.07	-0.01, 0.03	0.03, 0.12	-0.01, 0.07	-0.20, -0.09

CSIE	0.10	-	0.07	-	-0.24
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Note: $A = (M \cdot X)$; $B = (M \cdot Y)$; C' = direct effect of X on Y, controlling for M; C = total effect of X on Y, not controlling for M; AB = proportion of effect that is mediated; b = mediated/indirect effect ($a \cdot b$); CI = confidence interval; CSIE: completely standardised indirect effect. * p value is less than .05. ** p value is less than .001.

Table 7. Mediation Models with GSE as mediator, with covariates

	Model 1 X = stigma M = control Y = HRQoL Covariates: Age of symptom onset; age of diagnosis	Model 2 X = stigma M = control Y = anxiety Covariates: Age of symptom onset; relationship status	Model 3 X = stigma M = control Y = depression Covariates: relationship status; living status	Model 4 X = stigma M = control Y = stress Covariates: relationship status; living status
A				
b	-0.15**	-0.15**	-0.15**	-0.15**
CI	-0.20, -0.10	-0.20, -0.10	-0.20, -0.11	-0.20, -0.11
B				
b	-0.28**	-0.13	-0.45**	-0.16
CI	-0.38, -0.17	-0.28, 0.03	-0.62, -0.28	-0.34, 0.02
C'				
b	0.26**	0.20**	0.31**	0.29**

CI	0.21, 0.30	0.14, 0.27	0.24, 0.38	0.21, 0.36
AB				
b	0.04	0.01	0.03	0.01
CI	0.02, 0.07	-0.003, 0.03	0.02, 0.07	-0.002, 0.03
CSIE	0.10	-	0.07	-

Note: $A = (M \cdot X)$; $B = (M \cdot Y)$; C' = direct effect of X on Y, controlling for M; C = total effect of X on Y, not controlling for M; AB = proportion of effect that is mediated; b = mediated/indirect effect ($a \cdot b$); CI = confidence interval; $CSIE$: completely standardised indirect effect. * p value is less than .05. ** p value is less than .001.

Model 1: Mediational regressions for stigma, perceived control and HRQoL

Mediation analyses indicated that stigma significantly predicted perceived control (pathway A: $b = -0.26$, 95% CI $[-0.34, -0.18]$, $p < .001$) and perceived control predicted ratings of HRQoL (PDQ) (pathway B: $b = -0.09$, 95% CI $[-.16, -0.03]$, $p < .05$; see table 4).

Perceived control was found to be a significant mediator within the model (pathway AB: $b = 0.02$), with the confidence interval not crossing zero (BC 95% CI $[0.01, 0.05]$); this indicates that perceived control plays a mediating role in the relationship between stigma and HRQoL.

The direct effect between stigma and HRQoL was found to be significant when controlling for the effect of the mediational variable of perceived control (C' : $b = 0.26$, 95% CI $[0.22, 0.31]$, $p < .001$). The completely

standardised indirect effect indicates that as stigma increased by 1 SD, PDQ scores increased by 0.06 SD due to the effect of perceived control. Thus, as a result of the influence of perceived control, as stigma increased, HRQoL decreased.

When controlling for the variables of age, symptom onset and age of diagnosis, all pathways of the model remained significant (see Table 5 for details) and the completely standardized indirect remained the same (0.06).

Model 2: Mediation regressions for stigma, perceived control and anxiety

The second unadjusted mediation model found stigma to significantly predict perceived control (pathway A: $b = -0.26$, 95% CI $[-0.34, -0.18]$, $p < .001$; see table 4).

Perceived control did not significantly predict anxiety in

the model (pathway B: $b = -0.01$, 95% CI $[-0.11, 0.09]$, $p > .05$). The overall indirect effect was (pathway AB: $b = 0.003$) and the confidence interval contained zero (BC 95% CI $[-0.03, 0.03]$) suggesting that there was a non-significant effect for the mediating role of perceived control within the model.

When adjusting for the variables of age, symptom onset and relationship status, again only pathway A was significant within the model (see Table 5 for details).

Model 3: Mediational regressions for stigma, perceived control and depression

The third unadjusted mediation model found stigma to significantly predict perceived control (pathway A: $b = -0.26$, 95% CI $[-0.34, -0.18]$, $p < .001$; see table 4).

Perceived control significantly predicted depression in the model (pathway B: $b = -0.26$, 95% CI $[-0.37, -0.15]$,

$p < .001$). The overall indirect effect for perceived control (pathway AB: $b = 0.07$), was found to be significant with a confidence interval that did not contain zero (BC 95% CI [0.03, 0.11]). This indicates that perceived control plays a mediating role in the relationship between stigma and depression. The direct effect between stigma and depression remained significant when controlling for the effect of the mediational variable of perceived control (C' : $b = 0.32$, 95% CI [0.25, 0.39], $p < .001$). The completely standardised indirect effect indicates that as stigma increased by 1 SD, DASS-D scores increased by 0.11 SD, thus, as stigma increased, depression increased as a result of perceived control.

When adjusting for the variables for relationship status and living arrangements, all pathways of the model remained significant (see Table 5 for details) and the completely standardised indirect effect reduced (0.10).

Model 4: Mediation regressions for stigma, perceived control and stress

The fourth unadjusted mediation model found stigma to significantly predict perceived control (pathway A: $b = -0.26$, 95% CI $[-0.34, -0.18]$, $p < .001$; see table 4).

Perceived control was not a significant predictor of stress in the model (pathway B: $b = -0.08$, 95% CI $[-0.19, 0.03]$, $p > 0.05$). The overall indirect effect for perceived control (pathway AB: $b = 0.02$), was found to be non-significant with a confidence interval that contained zero (BC 95% CI $[-0.01, 0.06]$). This suggests that perceived control did not play a mediating role in the relationship between stigma and stress.

When adjusting for the variables of living arrangements and relationship status within the model, again only pathway A was significant (see Table 5 for details)

Model 5: Mediation regression for stigma, perceived control and positive affect

The fifth unadjusted mediation model found stigma to significantly predict perceived control (pathway A: $b = -0.26$, 95% CI $[-0.34, -0.18]$, $p < .001$; see table 4).

Perceived control was a significant predictor of positive affect (pathway B: $b = 0.52$, 95% CI $[0.43, 0.62]$, $p < .01$). The overall indirect effect for perceived control (pathway AB: $b = -0.14$), was found to be significant with a confidence interval that did not cross zero (BC 95% CI $[-0.19, -0.09]$). This suggests that perceived control mediated the relationship between stigma and the experience of positive affect.

The direct effect between stigma and positive affect was found to be significant when controlling for the effect of the mediational variable of perceived control (C' : $b = -0.13$, 95% CI $[0.19, 0.07]$, $p < .001$). The completely

standardised indirect effect indicates that as stigma increased by 1 SD, PANAS scores decreased by -0.23 SD, thus, as stigma increased, positive affect decreased due to the effect of perceived control.

There were no covariates that correlated with positive affect. Thus, an adjusted mediational regression was not required.

Mediational regressions using the GSE

The GSE was interchanged as the mediator in the regression analyses, to examine if the results were comparable to those with the PUKSoPC as mediator.

Table 6 indicates that the results of the GSE were similar to those for the PUKSoPC. All pathways showed the same direction of the relationship between the predictor, mediator and outcome. All the PUKSoPC significant pathways were also found to be significant

when the GSE was used as mediator. When controlling for confounds in the model, the significant pathways remained similar to the unadjusted GSE model and comparable to the adjusted PUKSoPC (see Table 7).

The two models which were found to be non-significant using the PUKSoPC as mediator (DASS-A; DASS-S) were also found to be non-significant when the GSE was used. When the mediator was changed, the completely standardised indirect effect was comparable to that of the PUKSoPC (see Table 6).

Discussion

This study examined whether the perception of control plays a mediating role in the relationship between stigma and HRQoL and stigma and emotional well-being.

Stigma correlated with all outcome measures in the expected direction (greater stigma, poorer wellbeing).

Moderate effect sizes were found between stigma and perceived control, positive affect and anxiety. Large effect sizes were found between stigma and stress, depression and HRQoL

Perceived control significantly mediated the relationship between stigma and HRQoL, depression and positive affect. All pathways within these models were significant, including when covariates were controlled for. The largest completely standardised effect size was for the mediated relationship between stigma and positive affect.

Perceived control did not mediate the relationship between stigma and anxiety and stress.

The mediating effect of perceived control supports the importance placed upon it within health behaviour models such as Leventhal's self-regulatory model of illness representation (Leventhal, Nerenz & Steele, 1984). This model provides a framework of understanding how an individual's health beliefs may facilitate adjustment to a health condition (Leventhal, Nerenz & Steele, 1984). Control is an important component of these beliefs and the model cumulatively can explain the various influences on and responses to a chronic condition such as PD. In addition, the current findings provide further support to the growing literature that emphasises the role of perceived control (Felton & Revenson, 1984), particularly for those with PD (Simpson, Lekwuwa & Crawford, 2013). From a theoretical perspective, the association between the loss of control and depression has long been established in

empirical research (Seligman & Groves, 1970). For example, learned helplessness may arise as a result of having limited or no control and this state has been associated with negative affect and is often considered to lead to depression (Nowicka-Sauer et al., 2017).

However, the lack of a relationship between stigma, control and anxiety, while not hypothesised, is also consistent with other research. In this current study, both measures of perceived control (PUKSoPC; GSE) were only weakly associated with anxiety, and neither were a predictor of anxiety in regression models. Other research reports a weak or no association between perceived control and anxiety (Evans & Norman, 2009; Simpson et al., 2013), and a non-significant predictive effect of perceived control on anxiety in PD (Evans & Norman, 2009) and MS (Jopson & Moss-Morris, 2003; Vaughan, Morrison & Miller, 2003). Thus, although the

finding that perceived control did not mediate nor predict anxiety in the models was initially surprising, research supports the non-significant relationship within more complex statistical analyses. The implications from these findings suggest that targeting interventions that focus on increasing perceived control, may not be as effective in decreasing anxiety or stress for individuals with PD who report stigma. Interventions, therefore, should focus on decreasing stigma in society which would have a beneficial effect on reducing anxiety and stress for individuals with PD.

Clinical Implications

Interventions should acknowledge the effect of stigma, through the direct pathway and the indirect pathway, via perceived control. Reducing stigma is complicated and requires coordinated effort on a number of levels (Corrigan, 2004). Successful anti-stigma campaigns are

notoriously difficult to achieve for health-related conditions (Evans-Lacko, London, Little, Henderson & Thornicroft, 2010) and the challenges in achieving this should not be underestimated. However, approaches should aim to decrease stigma experiences by a number of different routes including by increasing societal awareness of PD (Devlin, MacAskill & Stead, 2007).

Clinical psychologists may assist with this aim, by sharing information to aid public understanding.

Information provision is a major component of all stigma reduction campaigns (Byrne, 2000) but also needs to be supplemented by rigorous efforts to address misleading information or discriminatory practices. Developing a greater public understanding may help reduce any concerns or misconceptions surrounding the condition, which may also serve to diminish stigmatisation. This could be achieved by utilising Parkinson UK's expertise

in designing campaigns, in order to target stigma associated with the condition. Utilising this expertise is beneficial given that stigma is socially constructed, and also perceived control is impacted by broader societal issues. Developing stigma-reducing campaigns may also encourage individuals to become more involved with organisations such as Parkinson's UK and may lead to a two-fold benefit of reducing stigma and increasing individuals' perceived control.

In addition, clinical psychologists could inform guidelines for professionals working with individuals with PD (see British Psychological Society, 2009) in order to reduce stigma and enhance perceptions of control, HRQoL and emotional wellbeing.

It is likely that interventions that aim to increase perceived control may also be beneficial in increasing an

individual's wellbeing and may counter the effect of stigma. Cognitive behavioural therapy (CBT) has been shown to be effective in increasing individuals' perception of control and emotional wellbeing (Kroenke, & Swindle, 2000). While individual therapy has shown to be effective in increasing perceived control, it is not the only approach to influencing an effect on perceived control. It is likely that obtaining a sense of perceived control can be gained from a number of factors, and it may be useful to consider using broad systemic approaches. Individuals with PD are acting and responding to their environment, thus it may be beneficial to focus at a systemic level. Family and friends of individuals with PD could be informed of the importance of perceived control and how it has a mediating effect. Family and friends could be made aware of what might help to increase perceived control

in everyday life for individuals with PD. By sharing this level of understanding with family and friends, it may help others to think of creative ways to help develop a sense of perceived control in everyday life. This approach may broaden the applicability of research findings to beyond the therapy room. The use of a broader community-based approach has been shown to increase wellbeing for older adults (Devlin et al., 2007). Clinical psychologists could help to generate community-based intervention ideas, collaboratively with individuals with PD to help increase perceived control.

Strengths, limitations and proposals for future research

The purpose of this study was to examine the nature of the relationship between stigma, perceived control and wellbeing. In this way the current research complements Parkinson UK's (2015) strategy of increasing our

understanding of control and knowledge of how individuals with PD can increase their sense of control. Future research could examine whether one of the components of stigma predicts certain dimensions of HRQoL (e.g. enacted stigma could predict activities of daily living). With a greater understanding of stigma (i.e. its separate forms and how these are related to the individual components of HRQoL) interventions may be tailored more appropriately, at either an individual or societal level. For example, if enacted stigma plays a significant role in HRQoL, it may be more appropriate to increase awareness and understanding of the nature of PD through various media channels. Having a detailed understanding of the type of stigma and its relationships may provide a cost-effective use of psychology resource.

Equally it may be that psychological interventions designed to increase emotional wellbeing are likely to increase an individual's sense of control. These relationships may be bidirectional and/or circular, therefore interventions that enhance wellbeing for individuals with PD may reduce stigma experience. For example, individuals who have high levels of positive affect may perceive their experiences as positive and may have less negative bias, compared to individuals with higher levels of negative affect. There may be an association between individuals with higher levels of positive affect, perceiving less experiences of felt stigma.

The use of the member-informed scale of perceived control (PUKSoPC) ensures that aspects of control that are important for those experiencing PD are examined. Thus, the scale is considered to have good face validity

(Simpson et al., in press). Utilising two measures of control (PUKSoPC and GSE), allowed for comparison of the PUKSoPC with the well-validated GSE. When examining the data for PUKSoPC and GSE, the patterns were similar, with the variance PUKSoPC accounted for comparable to that of the GSE. When compared with the PUKSoPC, the GSE accounted for more variance in HRQoL and less variance for anxiety. However, this difference was minimal. As the results from the PUKSoPC were comparable to those from the well-validated GSE, this study presents further validation of the PUKSoPC for use with individuals with PD.

The participants in this study reported low levels of stigma, depression and moderately high levels of perceived control. Since the majority of the data was collected within a short time period (two weeks) and with low attrition, it may be suggested that the participants

who took part were highly motivated. Notwithstanding these factors, the mediating effect of perceived control was found in this study. The results of the current paper therefore highlight the importance of perceived control in explaining some of the relationship between stigma and emotional wellbeing and HRQoL. Since perceived control has shown a mediating effect in low reported stigma conditions it may be useful to capture the experience of individuals with PD who report lower levels of control, higher levels of stigma and may have reduced functioning to examine the mediating strength of control.

The study used online recruitment and was advertised through Parkinson's UK. This may have selected a sample of individuals who may be highly literate and/or motivated due to the fact that they have proactively become a member of a third-sector organisation.

Therefore, the findings could be different for individuals with PD who do not have computer access or are not members of a charity.

The study was only available in English, and although individuals were permitted to complete the survey with support, comprehending the survey and the concept of stigma may not be translatable to other languages or cultures. Individuals from Eastern cultures may be more experienced in viewing concepts, such as wellbeing, from a dual perspective (Spencer-Rodgers, Peng, Wang & Hou, 2004); in turn this may influence their reports of the concept and the meaning of the score. Thus, the findings of the present study may be limited in its generalisability cross-culturally.

The sample of participants was predominantly white with only two individuals identifying themselves as Asian.

Thus, this may reduce the representativeness of the findings of the study, as the sample may not capture the diversity in population of individuals experiencing PD in the UK. It may be beneficial for replication to be conducted with a sample that more broadly represents the population of individuals with PD. This would increase the ecological validity and may strengthen the findings of the current study and the implications that are proposed.

Given the cross-sectional design of the study, the findings provide a snapshot of how perceived control affects the relationship between stigma and variables of HRQoL. With a progressive condition, such as PD, the condition may become more visible and therefore more visible to others. Increasing visibility may result in higher experiences of stigma (Jones et al., 1984). The experience of perceived control may also change over

time with a changing course of the condition (Leventhal, Nerenz & Steele, 1984). Longitudinal studies may provide a more detailed picture of how these relationships may change over time.

Conclusion

The findings of this study inform our understanding of the nature of the relationship between stigma and HRQoL and emotional wellbeing for individuals with PD. The findings provide further support for the role of perceived control in individuals with chronic health conditions. Perceived control plays an important role in mediating the relationship between stigma and HRQoL, stigma and depression and stigma and positive affect. Interventions should target control to help enhance individuals' HRQoL and aspects of emotional wellbeing. Systemic interventions should be utilised to increase control in everyday life for individuals with PD.

Interventions should also target stigma and its impact on individuals' wellbeing, through raising awareness and public understanding of PD. Future research should further examine stigma and its defined forms with the individual components of HRQoL, to elucidate the relationships further. In addition, conducting more complex statistical models would allow for examination of more complex relationships including whether bidirectional relationships exist.

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Appendix A. Author

Guidelines

The aim of the British Journal of Health Psychology is to provide a forum for high quality research relating to health and illness. The scope of the journal includes all areas of health psychology as outlined in the Journal Overview. The types of paper invited are:

- papers reporting original empirical investigations, using either quantitative or qualitative methods, including reports of interventions in clinical and non-clinical populations;
- theoretical papers which report analyses on established theories in health psychology;
- we particularly welcome review papers, which should aim to provide systematic overviews, evaluations and

interpretations of research in a given field of health psychology; and methodological papers dealing with methodological issues of particular relevance to health psychology.

All papers published in The British Journal of Health Psychology are eligible for Panel A: Psychology, Psychiatry and Neuroscience in the Research Excellence Framework (REF).

1. Circulation

The circulation of the Journal is worldwide. Papers are invited and encouraged from authors throughout the world.

2. Length

Papers describing quantitative research (including reviews with

quantitative analyses) should be no more than 5000 words (excluding the abstract, reference list, tables and figures). Papers describing qualitative research (including reviews with qualitative analyses) should be no more than 6000 words (including quotes but excluding the abstract, tables, figures and references). The Editors retain discretion to publish papers beyond this length in cases where the clear and concise expression of the scientific content requires greater length.

3. Editorial policy

The Journal receives a large volume of papers to review each year, and in order to make the process as efficient as possible for authors and editors alike, all papers are initially examined by the

Editors to ascertain whether the article is suitable for full peer review. In order to qualify for full review, papers must meet the following criteria:

- the content of the paper falls within the scope of the Journal
- the methods and/or sample size are appropriate for the questions being addressed
- research with student populations is appropriately justified
- the word count is within the stated limit for the Journal (i. e. 5000 words, or 6000 words for qualitative papers)

4. Submission and reviewing

All manuscripts must be submitted via <http://www.editorialmanager.com/bjhp/default.aspx>. The Journal operates a policy of anonymous

(double blind) peer review. For submission instructions and all other information, please visit: <http://www.wileyonlinelibrary.com/journal/bjhp>. The journal employs a plagiarism detection system. By submitting your manuscript to this journal you accept that your manuscript may be screened for plagiarism against previously published works.

5. Manuscript requirements

- Contributions must be typed in double spacing with wide margins. All sheets must be numbered.
- Manuscripts should be preceded by a title page which includes a full list of authors and their affiliations, as well as the corresponding authors contact details.

- For articles containing original scientific research, a structured abstract of up to 250 words should be included with the headings: Objectives, Design, Methods, Results, Conclusions. Review articles should use these headings: Purpose, Methods, Results, Conclusions. As the abstract is often the most widely visible part of your paper, it is important that it conveys succinctly all the most important features of your study.
- Statement of Contribution: All authors are required to provide a clear summary of what is already known on this subject? and what does this study add? Authors should identify existing research knowledge relating to the specific research question and give a summary of the new knowledge added by your study. Under

each of these headings, please provide 2-3 (maximum) clear outcome statements (not process statements of what the paper does); the statements for what does this study add? should be presented as bullet points of no more than 100 characters each.

- . Conflict of interest statement: We are now including a brief conflict of interest statement at the end of each accepted manuscript. You will be asked to provide information to generate this statement during the submission process.
- . The document must be anonymous. Please do not mention the authors names or affiliations (including in the Method section) and always refer to any previous work in the third person.
- . Tables should be typed in double spacing, each on a separate page with

a self-explanatory title.

Tables should be comprehensible without reference to the text.

They should be placed at the end of the manuscript but they must be mentioned in the text.

- . Figures can be included at the end of the document or attached as separate files, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns, lines and shading should be avoided. Captions should be listed on a separate sheet. The resolution of digital images must be at least 300 dpi. All figures must be mentioned in the text.
- . For reference citations, please use APA style.
- . S I units must be used for all measurements, rounded off to practical values if appropriate, with the imperial

equivalent in parentheses.

- . In normal circumstances, effect size should be incorporated.
- . Authors are responsible for acquiring written permission to publish lengthy quotations, illustrations, etc. for which they do not own copyright.
- . Manuscripts describing clinical trials are encouraged to submit in accordance with the CONSORT statement on reporting randomised controlled trials.
- . Manuscripts reporting systematic reviews and meta-analyses are encouraged to submit in accordance with the PRISMA statement.
- . Manuscripts reporting interventions are encouraged to describe them in accordance with the TIDieR checklist.

6. Supporting Information

We strongly encourage submission of protocol papers or trial registration documents, where these are in the public domain, to allow reviewers to assess deviations from these protocols. This will result in reviewers being unblinded to author identity.

Supporting Information can be a useful way for an author to include important but ancillary information with the online version of an article. Examples of Supporting Information include appendices, additional tables, data sets, figures, movie files, audio clips, and other related nonessential multimedia files.

Supporting Information should be cited within the article text, and a descriptive legend should

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OnlineOpen is available to authors of primary research articles who wish to make their article available to non-subscribers on publication, or whose funding agency requires grantees to archive the final version of their article. With OnlineOpen, the author, the authors funding agency, or the authors institution pays a fee to ensure that the article is

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Author Services enables authors to track their article – once it has been accepted – through the production process to publication online and in

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If your paper is accepted, the author identified as the formal corresponding

author for the paper will receive an email prompting them to login into Author Services, where via the Wiley Author Licensing Service (WALS) they will be able to complete the licence agreement on behalf of all authors on the paper. If the OnlineOpen option is not selected the corresponding author will be presented with the copyright transfer agreement (CTA) to sign. The terms and conditions of the CTA can be previewed in the samples associated with the Copyright FAQs. If the OnlineOpen option is selected the corresponding author will have a choice of the following Creative Commons Licence Open Access Agreements (OAA): - Creative Commons Attribution Non-Commercial Licence (CC-BY-NC)

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10. Colour illustrations

Colour illustrations can be accepted for publication online. These would be reproduced in greyscale in

the print version. If authors would like these figures to be reproduced in colour in print at their expense they should request this by completing a Colour Work Agreement form upon acceptance of the paper.

11. Pre-submission

English-language editing

Authors for whom English is a second language may choose to have their manuscript professionally edited before submission to improve the English. A list of independent suppliers of editing services can be found in <http://authorservices.wiley.com>.

All services are paid for and arranged by the author, and use of one of these services does not guarantee acceptance or preference for publication.

12. The Later Stages

The corresponding author will receive an email alert containing a link to a web site. The proof can be downloaded as a PDF (portable document format) file from this site. Further instructions will be sent with the proof. Excessive changes made by the author in the proofs, excluding typesetting errors, will be charged separately.

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Early View articles are complete and final. They have been fully reviewed, revised and edited for publication, and the authors final corrections have been incorporated. Because they are in final form, no changes can be made after online publication. The nature of Early View articles means that they do not yet have volume, issue or page numbers, so they cannot be cited in the traditional way. They are cited using their Digital Object Identifier (DOI) with no volume and issue or pagination information.

Section Three: Critical Appraisal

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Abstract

The findings that perceived control mediated the relationship between stigma and aspects of psychological wellbeing and health-related quality of life, are critically appraised in this paper. Factors which may influence the study findings, such as study design, epistemological position and recruitment considerations are outlined. Personal reflections of the research process and proposals for future research are provided.

A quantitative study of cross sectional design was used to examine whether the perception of control mediates the relationship between stigma and factors of wellbeing. Correlational analyses indicated that a number of demographic and clinical factors significantly correlated with the experience of stigma and the assessed factors of wellbeing.

The study found perceived control to be a significant mediator in the relationship between stigma and depression, health-related quality of life (HRQoL) and positive affect, but not between stigma and anxiety or stress.

The findings indicate the potential importance of perceived control in contributing to some aspects of wellbeing for individuals with Parkinson's disease (PD).

This paper will discuss study design considerations and strengths and limitations of the research. Personal reflections will be provided and the link between stigma and disablism discussed. Considerations for future research will also be proposed.

Study Design

Use of quantitative methods

I adopted a quantitative methodology to further examine the roles of stigma and perceived control. This approach allows for information to be gathered on the role that a particular variable (e.g. perceived control) may have in relation to stigma and wellbeing. The choice of research design is underpinned by my epistemological positivist perspective that the truth is 'real' and discoverable.

Compared to qualitative approaches, quantitative methods facilitate the investigation of concepts and experiences that are shared across a particular population, thus providing detail that is applicable to larger samples. Gaining knowledge of concepts and relationships across a larger scale allows for a more representative way to apply this information to theoretical frameworks. Moreover, the increased

representativeness of findings allows for the generation of clinical and systemic proposals, which may influence future policies and broader service provision.

Although it may be argued that qualitative approaches provide detailed and individualised accounts of experiences, the relationships between perceived control, stigma and wellbeing have been researched from a qualitative perspective (Maffoni, Giardini, Pierobon, Ferrazzoli & Frazzitta, 2017).

Online participation

The study was advertised online by Parkinson's UK (PUK). Since the researchers at Lancaster University have established good links with the charity, this may have helped in obtaining feedback on the proposed study and the recruitment of individuals. PUK have a large and active group of individuals who are willing to

take part in research. The participant quota for the survey was reached in under one week. This may indicate that using online research for individuals with PD is an acceptable medium. The study was designed to enable individuals to save their responses and return at a more convenient time should they feel fatigued or if they required the survey to be temporarily postponed. Although recruiting individuals quickly was beneficial to this thesis project, given the short recruitment period available, future studies may benefit by having a broader advertisement process.

Being computer-literate is a pre-requisite of participating in this study, which may have been a barrier to individuals who do not have experience in using computers. However human support could have been used (e.g. family or friends) and paper versions were

available to facilitate survey completion for individuals.

Paper versions of the survey were made available upon request and were returned freepost. Only two individuals stated this preference and returned their questionnaires by post.

The study was advertised online through PUK, thus potentially only being accessible to individuals who are computer literate who may have higher levels of perceived control and higher functioning with PD compared to individuals who are not connected to the charity.

PD affects individuals at a later stage in life, therefore individuals with PD who are computer-literate may reflect a particular demographic which may not be representative of the wider PD population. Research from the Office for National Statistics in the UK indicates

that 4.2 million people aged over the age of 65 have never used the internet and only 0.5 million have used it, but not in the last 3 months (Age UK, 2016). Therefore, using varied recruitment methods may capture a wider demographic of individuals with PD experience.

Completing online surveys has the advantage of wide geographical coverage, timely delivery and return, and are more cost-effective than hard-copy alternatives (Dillman, 2007). However, given the low number of older individuals who use the internet it may have been beneficial to advertise the study in a paper format.

Future studies may benefit from providing support with survey completion to capture a broad spectrum of experience from individuals with PD i.e. those with lower control who may require telephone assistance or human support.

When proposing this study, it was considered unlikely to lead to distress through participation. Nevertheless, details of appropriate support agencies were provided at the end of the study. The online, anonymous nature of this study does not allow us to assess if the survey results in any signs of distress, however, of the 329 individuals who accessed the survey, none of the participants used the given email address to provide their comments or feedback on taking part. In addition, it may be assumed that the location of the survey on the PUK website, may be visible to individuals who are active members of the charity and are potentially familiar with participating in research.

The use of validated measures

The study used a range of validated measures of stigma, control and factors of wellbeing. All the

measures used Likert scales to assess the factors.

Using validated and reliable scales ensures that the constructs of interest are being measured.

The Parkinson's Disease Questionnaire-8 (PDQ-8) measures quality of life (Jenkinson, Fitzpatrick, Peto, Dummert, Morley et al., 2012). However, one question pertains specifically to stigma and therefore there is the risk that the relationship between the Stigma Scale for Chronic Illnesses (SSCI; Rao, Choi, Victorson, Bode, Peterman, et al., 2009) and PDQ-8 is inflated.

Therefore, the data for the PDQ-8 were re-analysed, removing the stigma question. It is acknowledged this involves using a measure which properties are no longer stable and validated (Spector, 1992). When comparing the analyses of the PDQ-7 and PDQ-8 the significant effect of the mediator remains, and the completely

standardised indirect effect size is extremely similar (see Table 1 in appendix for details). Thus, it seems unlikely that the findings can be explained by this possible conceptual confound.

Personal reflections

My own experience of having a health condition has drawn me to research within the field of health psychology. I have first-hand experience of a condition which could be stigmatising and personally identify with the importance of control in relation to quality of life.

Through the exploration of this topic it is hoped that individuals with PD will be provided with a societal perspective of difference. My professional motivation in carrying out this study is to extend my knowledge and interest within health psychology. In addition, this study contributes to the research base and furthers

understanding in the field. Ultimately, I hope that in the future this knowledge will be applied to appropriate clinical work in health psychology.

Stigma and Disablism

As a result of society's lack of appreciation of difference, individuals with PD may experience a range of effects which impact their lives. Individuals with PD may feel and experience exclusion from society and perceive a sense of marginalisation (Maffoni et al., 2017). Society is generally constructed to meet the needs of individuals without disabilities. Structural barriers exist in society which may exclude and isolate individuals who are unable to access these arenas in the same way (structural disablism; Reeve, 2014 p92). It has been reported that individuals without disability can feel uncomfortable interacting or relating to individuals with

disabilities. These experiences reflect what Reeve (2005) has reported as psycho-emotional disablism. This is reinforced by the underrepresentation of disabled individuals in the media portrayed with meaningful, rich lives. Often, when disabled individuals are presented in the media the focus is on their disability (indirect disablism; Reeve, 2014, p93). Such cultural norms influence both individuals' perceptions of their own disabilities and create societal assumptions and stereotypes regarding individuals with disabilities (Thomas, 1999). For individuals with disabilities such as PD, experiences of direct, indirect and structural disablism may result in them developing the belief that they are inadequate and less valued; Reeve (2014, p95) referred to this as internalised oppression. Such individuals may avoid situations, attempt to pass as 'normal', or may over achieve in an attempt to distance

themselves from any perceived negative attributions related to their visible difference (Campbell, 2009). The effect of such stigma may have a detrimental effect on an individual's wellbeing (Reijnders, Ehrt, Weber, Aarsland, & Leentjens, 2008). Thus, interventions need to target stigma at a societal level to effect change for the individual with difference and increase societal understanding and acceptance.

Future research

The interrelated nature of stigma, control and well-being could be further explored, obtaining depth and richness in responses using qualitative methodology. It may also be beneficial to explore the related nature of these variables with individuals with other neuro-degenerative conditions such as Huntington's disease, motor neuron disease and multiple sclerosis. Given the visible

differences associated with these conditions it may be expected that control may have a similar mediating affect between stigma and factors of psychological wellbeing.

When comparing the results of the PUKSoPC and the GSE, the findings suggest that the PUK member-constructed scale of control compared favourably to that of the well-validated GSE scale. The co-variance between these scales and the outcomes was comparable with GSE accounting for a greater amount of variance in depression, and PUKSoPC accounting for more variance in positive affect. However, the difference in the amount of variance was minimal.

It may be that further studies, in addition to using quantitative methods, may complement their findings by simultaneously utilising mixed methodology to provide

subjective accounts of stigma experience, both perceived and enacted, and explore how this might be related to the experience of wellbeing for individuals with PD.

Conclusion

The findings from the empirical paper suggest that it may be beneficial for interventions to target stigma and perceived control in order to maximise the effect on psychological wellbeing. Although there may still be a place for individual interventions to tackle individuals' beliefs about visible difference, in my opinion, a broader approach is required to target the dimensions that underpin experiences of psycho-emotional disablism. In order to enhance inclusion, health professionals and others need to engage with these concepts and not be afraid of using vocabulary such as the word 'stigma'.

Avoiding contentious terms does not equate to the absence of experience.

Ultimately the findings of this study indicate that the perceptions of control play a mediating role in the relationship between stigma and certain aspects of wellbeing for individuals with PD. This suggests that increasing control and reducing stigma experience could improve psychological wellbeing.

To promote wellbeing for individuals with PD, health professionals should facilitate discussions that focus on increasing control and reducing stigma experience.

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**Appendix A. Table 1. Mediation model 1 with
PUKSoPC/GSE as mediator and PDQ-7 as outcome
variable**

	X = stigma M = control (PUKSoPC) Y = HRQoL	X = stigma M = control (GSE) Y = HRQoL
A		
b	-0.26**	-0.16**
CI	-0.34, -0.18	-0.21, -0.11
B		
b	-0.08*	-0.27**
CI	-0.15, -0.18	-0.37, -0.17
C'		
b	0.22**	0.20**
CI	0.18, 0.26	0.16, 0.24
C		
b	0.24**	0.24**
CI	0.20, 0.28	0.20, 0.28
AB		
b	0.02	0.04
CI	0.01, 0.05	0.02, 0.07
CSIE	0.06	0.11

Note: A = (M*X); B = (M*Y); C' = direct effect of X on Y,
controlling for M; C = total effect of X on Y, not

controlling for M; AB = proportion of effect that is mediated; b = mediated/indirect effect ($a*b$); CI = confidence interval; CSIE: completely standardised indirect effect. * p value is less than .05. ** p value is less than .001.

Section Four: Ethics

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Contents

Section 1

Ethics Documents

- 1.1** Ethics Application
- 1.2** Protocol
- 1.3** Figure 1. Online Survey
- 1.4** Figure 2. Approval Letter

Word count does not exceed 6,000 words (excluding figures and references)

1.1 Ethics Application

**Faculty of Health and Medicine Research Ethics
Committee (FHMREC)
Lancaster University**

Application for Ethical Approval for Research

*for additional advice on completing this form,
hover cursor over 'guidance'.*

**Guidance on completing this form is also
available as a word document**

**Title of Project: Stigma, perceived control and
wellbeing in individuals with Parkinson's disease**

Name of applicant/researcher: Danielle Verity

ACP ID number (if applicable)*:

Funding source (if applicable)

Grant code (if applicable):

***If your project has *not* been costed on ACP, you will also need to complete the Governance Checklist [\[link\]](#).**

Type of study

☐ Involves existing documents/data only, or the evaluation of an existing project with no direct contact with human participants. **Complete sections one, *two* and four of this form**

☒ Includes *direct* involvement by human subjects. **Complete sections one, *three* and four of this form**

SECTION ONE

1. Appointment/position held by applicant and Division within FHM Trainee Clinical Psychologist

2. Contact information for applicant:

E-mail: d.verity@lancaster.ac.uk

Telephone: 07872 334 826 (please give a number on which you can be contacted at short notice)

Address: Department of Clinical Psychology, Division of Health Research, Lancaster University, Lancaster, LA1 4YG

3. Names and appointments of all members of the research team (including degree where applicable)

Danielle Verity, Principal Researcher, Trainee Clinical Psychologist

Fiona Eccles, Lecturer in Health Research

Jane Simpson, Director of Education, DHR

3. If this is a student project, please indicate what type of project by marking the relevant box/deleting as appropriate: (please note that UG and taught masters projects should complete **FHMREC form UG-tPG**, following the procedures set out on the [FHMREC website](#))

PG Diploma ☐ Masters by research ☐
PhD Thesis ☐ PhD Pall. Care ☐

PhD Pub. Health ☐ PhD Org. Health & Well Being ☐
PhD Mental Health ☐ MD ☐

DClinPsy SRP ☐ [if SRP Service Evaluation, please also indicate here: ☐] DClinPsy Thesis ☒

4. Project supervisor(s), if different from applicant:

Dr Fiona Eccles, Dr Jane Simpson

5. Appointment held by supervisor(s) and institution(s) where based (if applicable): Dr Friona Eccles (Research Supervisor, Lecturer in Research Methods), Dr Jane Simpson (Field Supervisor, Director of Education for the Division of Health Research and Assistant Dean – Communications and Marketing for the Faculty of Health and Medicine).

SECTION TWO

Complete this section if your project involves existing documents/data only, or the evaluation of an existing project with no direct contact with human participants

1. Anticipated project dates (month and year)

Start date:

End date:

2. Please state the aims and objectives of the project (no more than 150 words, in lay-person's language):

Data Management

For additional guidance on data management, please go to [Research Data Management](#) webpage, or email the RDM support email: rdm@lancaster.ac.uk

3. Please describe briefly the data or records to be studied, or the evaluation to be undertaken.

4a. How will any data or records be obtained?

4b. Will you be gathering data from websites, discussion forums and on-line 'chat-rooms'?

4c. If yes, where relevant has permission / agreement been secured from the website moderator?

4d. If you are only using those sites that are open access and do not require registration, have you made your intentions clear to other site users?

4e. If no, please give your reasons

5. What plans are in place for the storage, back-up, security and documentation of data (electronic, digital, paper, etc)? Note who will be responsible for deleting

the data at the end of the storage period. Please ensure that your plans comply with the Data Protection Act 1998.

6a. Is the secondary data you will be using in the public domain?

6b. If NO, please indicate the original purpose for which the data was collected, and comment on whether consent was gathered for additional later use of the data.

Please answer the following question *only* if you have not completed a Data Management Plan for an external funder

7a. How will you share and preserve the data underpinning your publications for at least 10 years e.g. PURE?

7b. Are there any restrictions on sharing your data?

The data will not be made public due to the sensitive nature of the information.

8. Confidentiality and Anonymity

a. Will you take the necessary steps to assure the anonymity of subjects, including in subsequent publications?

b. How will the confidentiality and anonymity of participants who provided the original data be maintained?

9. What are the plans for dissemination of findings from the research?

10. What other ethical considerations (if any), not previously noted on this application, do you think there are in the proposed study? How will these issues be addressed?

SECTION THREE

Complete this section if your project includes *direct* involvement by human subjects

1. Summary of research protocol in lay terms (indicative maximum length 150 words):

The current research aims to examine the relationship between perceived stigma, control and psychological wellbeing, with individuals with Parkinson's disease (PD). PD affects the motor system, resulting in jerky movements, tremor and facial expression which conveys less emotion. Such visible symptoms can lead to individuals experiencing negative attitudes (stigma) by others or perceiving a sense of stigma, within a

particular context. Research have shown that feeling stigmatized can result in feeling disempowered and negatively impacts upon psychological wellbeing. It is thought that the perception of control plays a predictive role in the relationship between perceived stigma and outcomes of psychological wellbeing. This study aims to assess the variables of interest through Qualtrics survey and examine their related nature using a mediation regression analysis. It is hypothesised that the relationship between perceived stigma and indices of wellbeing will be mediated by perceived control.

2. Anticipated project dates (month and year only)

Start date: 09/2017

End date: 05/2018

Data Collection and Management

For additional guidance on data management, please go to [Research Data Management](#) webpage, or email the RDM support email: rdm@lancaster.ac.uk

3. Please describe the sample of participants to be studied (including maximum & minimum number, age, gender):

Individuals who self-identify as having Parkinson's disease will be eligible to take part in the research. The study will be powered to find a medium effect size for both the relationship between stigma and control and

the relationship between control and wellbeing. At a power of .8 and $p < .05$ approximately 70 participants will be needed (Fritz & MacKinnon, 2007) using a bias-corrected bootstrap for the mediation model (Hayes, 2012). The minimum number of participants to ensure the study is viable is 70, and the maximum is 150.

Participants must be aged 18 or over. There will be no other age, gender or other demographic restrictions for participation in the project.

Exclusion criteria: The survey will be written in English, thus individuals who may not be able to read this language will not be eligible for inclusion.

4. How will participants be recruited and from where? Be as specific as possible. Ensure that you provide the *full versions* of all recruitment materials you intend to use with this application (eg adverts, flyers, posters).

The survey will be advertised through Parkinson's UK's website, and will invite their members who self-identify as having a diagnosis of Parkinson's Disease to participate in the project. In addition, the survey will also be advertised on the Lancaster University DClinPsy webpage, to enable participants who are not members of Parkinson's UK but identify themselves as having PD, to participate. By reading about the survey online, the participants will be able to access a participant information sheet about the survey (which can be downloaded should they wish). They will be directed to the consent form, and will then be able to access the

survey to take part. Participants will also be given the option to complete the survey in a paper format, should they wish. The contact details of how to obtain a paper version will be provided on the participant information sheet, and a paper version will be posted to them.

5. Briefly describe your data collection and analysis methods, and the rationale for their use.

Participants will complete a survey either online or on paper.

Individuals will be asked to provide demographic and clinical data and complete several validated measures to determine if relationships exist between variables.

The survey will consist of the following: -

Demographic variables:

- Age
- Gender
- Ethnicity
- Work status
- Relationship status
- Living arrangements (alone, co-habiting, residential/nursing home)

Clinical Variables:

- Age of onset
- Time since diagnosis
- Taking medication

Validated Measures:

- The Depression Anxiety and Stress Scale (DASS-21; Lovibond & Lovibond, 1995). This is a well-validated short-form version of the original scale (Henry & Crawford, 2005) and has been used with a PD population (Dubrow-Marshall & Birtwell, 2016). The short-version is considered to be more acceptable to individuals completing the measure (Henry & Crawford, 2005).

- The positive subscale of the Positive and Negative Affect Schedule (PANAS; Watson, Clark & Tellegen, 1988) will be used to measure positive affect in PD in the last few weeks. The positive subscale alone will be used, as the in-depth evaluation of negative mood will be provided by the DASS-21. PANAS is a reliable and valid measure of assessing positive and negative affect in non-clinical populations (Crawford & Henry, 2004).

- The Parkinson's Disease Questionnaire (PDQ-8) will be used to measure wellbeing (Jenkinson, Fitzpatrick, Peto, Dummatt, Morley et al., 2012).

- The Parkinson's UK Scale of Perceived Control (PUKSoPC-15; Simpson, Chatzidamianos & Eccles, 2015) will be administered. Parkinson's UK members

helped in the development of this scale and it has been initially validated (Simpson et al., 2015).

- Stigma Scale for Chronic Illness (SSCI-24; Molina, Choi, Cella & Rao, 2013) measures both perceived and enacted (carried out) stigma.
- The General Self-Efficacy Scale (GSE-10; Jerusalem & Schwarzer, 1992) will be used to assess individuals' general beliefs in their ability to respond and problem solve situations. The scale is a reliable and valid measure for use with individual's experiencing PD. (Nilsson, Hagell & Iwarsson, 2015).

All data will be collated and downloaded into the statistical software package, SPSS. A mediation regression analysis will be conducted on the quantitative data, to establish if perceived control explains/accounts for the relationship between stigma and well-being

6. What plan is in place for the storage, back-up, security and documentation of data (electronic, digital, paper, etc.)? Note who will be responsible for deleting the data at the end of the storage period. Please ensure that your plans comply with the Data Protection Act 1998.

During the data collection, data will be stored within the Qualtrics survey, accessible only to the research team for this project. For individuals who have completed a hard-copy version, the paper consent form will be

scanned in and the data inputted onto SPSS. The original paper documents will be destroyed immediately after data input. At the end of the study the data will be sent to the academic supervisor using an electronically secure method of data transfer and stored in a password-protected file space on the university server or Box. Scanned in consent forms and data will be stored separately for ten years. It will be the responsibility of academic supervisor to delete the data after this time. The raw data will not be made publicly accessible on PURE due to the sensitive information gathered.

7. Will audio or video recording take place? ☒ no
☐ audio ☐ video

a. Please confirm that portable devices (laptop, USB drive etc) will be encrypted where they are used for identifiable data. If it is not possible to encrypt your portable devices, please comment on the steps you will take to protect the data. N/A

b What arrangements have been made for audio/video data storage? At what point in the research will tapes/digital recordings/files be destroyed? N/A

Please answer the following questions *only* if you have not completed a Data Management Plan for an external funder

8a. How will you share and preserve the data underpinning your publications for at least 10 years e.g. PURE?

The data will be stored for 10 years by the DClinPsy research co-ordinator under the direction of the Programme Director/Research Director, but will not be available on PURE.

8b. Are there any restrictions on sharing your data ?

The data provided will be sensitive in nature and will not be made publicly available in raw form.

9. Consent

a. Will you take all necessary steps to obtain the voluntary and informed consent of the prospective participant(s) or, in the case of individual(s) not capable of giving informed consent, the permission of a legally authorised representative in accordance with applicable law? yes

b. Detail the procedure you will use for obtaining consent?

Participants will read information about the study prior to providing their consent. For participants completing the survey online they will tick a series of statements and then a final statement saying that they consent to take part and the survey will not allow them to proceed until these boxes are ticked. For participants who decide to complete a paper version, a participant information sheet and consent form will be provided. Only

participants who have provided their consent and signed the form will be entered into the electronic database.

10. What discomfort (including psychological eg distressing or sensitive topics), inconvenience or danger could be caused by participation in the project? Please indicate plans to address these potential risks. State the timescales within which participants may withdraw from the study, noting your reasons.

There are no substantial risks anticipated with participating in this study. It may be possible for participants to become distressed while completing the survey. Participants will be informed prior to commencing the study that they can opt out at any time during survey completion. However, due to the anonymity of participation, their data cannot be removed after they have agreed to take part. After starting the survey, participants will have 7 days to complete the survey, after this time participants will not be able to edit or input data, and responses will be automatically submitted. The participant information sheet will include sources of support and participants will be reminded of these at the end of the electronic survey.

11. What potential risks may exist for the researcher(s)? Please indicate plans to address such risks (for example, noting the support available to you; counselling considerations arising from the sensitive or distressing nature of the research/topic; details of the

lone worker plan you will follow, and the steps you will take).

No risks anticipated for researcher

12. Whilst we do not generally expect direct benefits to participants as a result of this research, please state here any that result from completion of the study.

There will be no direct benefits for participants for taking part in the research. However, the findings of the study will be shared with Parkinson's UK and their members. Participants will also be able to ask the researcher for a copy of the results.

13. Details of any incentives/payments (including out-of-pocket expenses) made to participants:

No incentives will be paid.

14. Confidentiality and Anonymity

a. Will you take the necessary steps to assure the anonymity of subjects, including in subsequent publications? yes

b. Please include details of how the confidentiality and anonymity of participants will be ensured, and the limits to confidentiality.

Participation will be completely anonymous and no directly identifiable information will be gathered. Before

completing the survey, participants will be informed that they are free to stop the survey at any point, however their data cannot be identified for removal.

15. If relevant, describe the involvement of your target participant group in the *design and conduct* of your research.

Parkinson's UK have previously identified that obtaining a sense of control is important for their members. The scale of perceived control that will be used has been developed by and for its members. Service user involvement was sought at the design stage of the project and their feedback provided details on the acceptability of the study. In addition, they also provided information on the content and format, to facilitate accessibility and aid engagement. Feedback from the Patient and Public Involvement forum group for Parkinson's UK members amended the language of the Participant Information Sheet and Consent Form to aid clarity. In addition, they highlighted that the benefits for members to take part in the study needed to be more clearly expressed. Thus, these recommendations were addressed prior to submitting to the ethics board.

16. What are the plans for dissemination of findings from the research? If you are a student, include here your thesis.

The project will be written as a final year thesis project for a DClinPsy. In addition, the Parkinson's UK charity

will be informed of the outcome of the study and provided with a short report, which states the results and implications of the study in language which is accessible to charity members and personnel. The findings of the study will be submitted to relevant journals and may be presented at conferences and will be presented to peers and staff at the DClinPsy thesis presentation day.

17. What particular ethical considerations, not previously noted on this application, do you think there are in the proposed study? Are there any matters about which you wish to seek guidance from the FHMREC?

I have a disability and my support worker - Amanda Boland, will assist with tasks related to the project. In this way, Amanda may have access to the raw data. Amanda has been informed of the duty of confidentiality and provided her agreement to adhere to ethical principles for the purpose of research.

SECTION FOUR: signature

Applicant electronic signature:

Date

Student applicants: please tick to confirm that you have discussed this application with your supervisor, and that they are happy for the application to proceed to ethical review ☐

Project Supervisor name (if applicable):

Eccles Date application discussed

Submission Guidance

1. SUBMIT YOUR FHMREC APPLICATION BY EMAIL TO DIANE HOPKINS (d.hopkins@lancaster.ac.uk) as two separate documents:

i. **FHMREC application form.**

Before submitting, ensure all guidance comments are hidden by going into 'Review' in the menu above then choosing *show markup>balloons>show all revisions in line*.

II. **Supporting materials.**

Collate the FOLLOWING MATERIALS FOR YOUR STUDY, IF RELEVANT, INTO A SINGLE WORD DOCUMENT:

A.YOUR FULL RESEARCH PROPOSAL
(BACKGROUND, LITERATURE REVIEW,

METHODOLOGY/METHODS, ETHICAL CONSIDERATIONS).

- b. Advertising materials (posters, e-mails)
- c. Letters/emails of invitation to participate
- d. Participant information sheets
- e. Consent forms
- f. Questionnaires, surveys, demographic sheets
- g. Interview schedules, interview question guides, focus group scripts
- h. Debriefing sheets, resource lists

Please note that you DO NOT need to submit pre-existing measures or handbooks which support your work, but which cannot be amended following ethical review. These should simply be referred to in your application form.

2. Submission deadlines:

- i. Projects including direct involvement of human subjects **[section 3 of the form was completed]**. The *electronic* version of your application should be submitted to DIANE HOPKINS **by the committee deadline date**. Committee meeting dates and application submission dates are listed on the [FHMREC website](#). Prior to the FHMREC meeting you may be contacted by the lead reviewer for further clarification of your application. Please ensure you are available to attend the committee meeting (either in person or via

telephone) on the day that your application is considered, if required to do so.

- ii. The following projects will normally be dealt with via chair's action, and may be submitted at any time. **[Section 3 of the form has *not* been completed, and is not required]**. Those involving:

- a. existing documents/data only;
- b. the evaluation of an existing project with no direct contact with human participants;
- c. service evaluations.

3. You must submit this application from your Lancaster University email address, and copy your supervisor in to the email in which you submit this application

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1.2 Protocol

**Stigma, perceived control and wellbeing in
individuals with Parkinson's disease**

Name: Danielle Verity

Supervisors: Fiona Eccles and Jane Simpson

Version 1

Parkinson's disease (PD) is a neurodegenerative condition, which primarily affects the motor system, resulting in tremor, rigidity and slowness of movement (Jankovic, 2008). However, other difficulties are also often present including problems with sleep and cognition as well as psychological difficulties such as low mood and anxiety (Menza & Marsh, 2006). PD is the second most common neurodegenerative condition after Alzheimer's Disease (Leroi, Collins, & Marsh, 2006). In the United Kingdom PD has a prevalence of approximately 27.4 per 10,000, which equates to around 127,000 individuals (Parkinson's UK, 2009).

Individuals with PD are also impacted by the stigma/negative attitudes surrounding their condition (Ma, Saint-Hilaire, Thomas & Tickle-Degnen, 2016). Stigma can lead to a feeling of shame and

embarrassment, as a result of self-perceived inadequacy through loss of autonomy, visible symptoms and the experience of others' attitudes and beliefs within the social context that surrounds the person with PD (Maffoni, Giardini, Pierobon, Ferrazzoli & Frazzitta, 2017). In addition, negative attitudes have consequences for individuals with stigmatising conditions, which may result in reduced social support, social exclusion and occupational loss (Goffman, 1963; Weiner, Perry & Magnusson, 1988). The felt sense of stigma can have detrimental effects on an individual's self-esteem and contributes to reduced emotional wellbeing (Link & Phelan, 2001; Rao, Choi, Victorson, Bode, Peterman, Heinmann et al., 2009; Schrag, Jahanshahi, Quinn, 2001).

An individual's perceived sense of control has also been shown to predict psychological outcomes in individuals with health conditions, including PD (see Hagger & Orbell, 2003; Garlofsky, Overton & Simpson, 2016). For individuals with PD, obtaining a sense of control in relation to their condition may not be possible given its degenerative nature. However, perceived control over other life domains may be more important (Eccles & Simpson, 2011).

Thus, both perceptions of stigma and control have been shown to affect psychological outcomes for people with PD. However, currently the relationship between these psychological constructs is unclear. Results from a study with another degenerative condition (Alzheimer's disease), found that negative social interactions which were marked by disempowerment, stigmatisation and

exclusion resulted in decreases in a sense of personal control (Harris & Sterin, 1999). Consequently, the proposed study aims to assess whether perceived control mediates the association between perceived stigma and psychological outcomes for people with PD.

The findings of the study will be used to inform clinical interventions with PD individuals. In addition, the results may help to influence the creation of campaigns to reduce stigma at a broader level.

Individuals with PD will be asked to complete a number of validated measures. The data once collated will be statistically examined, with the intention of constructing a mediational regression model (Hayes, 2012) of the data.

Method

Participants

This study will be powered to find a medium effect size for both the relationship between stigma and control and the relationship between control and wellbeing. At a power of .8 and $p < .05$ approximately 70 participants will be needed (Fritz & MacKinnon, 2001) using a bias-corrected bootstrap for the model (Hayes, 2012).

Inclusion criteria

- Individuals who self-report a diagnosis of Parkinson's disease will be eligible to take part in the project.
- The survey will be written in English; thus, participants must have sufficient knowledge of written English to take part
- Participants will be able to complete the research measures either alone or with support.

Design

The study will be a cross-sectional survey using quantitative measures. The data will be quantitatively examined and a mediation analysis will be conducted using Hayes process tool (Hayes, 2012) to examine whether perceived control mediates the relationship between stigma and psychological distress and quality of life.

The dependent variable will be scores of emotional wellbeing: the positive subscale of the Positive And Negative Affect Schedule (Watson, Clark & Tellegen, 1988), the Parkinson's Disease Questionnaire (PDQ-8) Jenkinson et al., 2012) and the three components of the Depression Anxiety and Stress Scale (Lovibond & Lovibond, 1995) – see materials section for details on reliability and validity.

The predictor variables will be perceived stigma, measured using the Stigma Scale for Chronic Illness (SSCI -24;

Molina, Choi, Cella & Rao, 2013) measured using and demographic and clinical variables (see below for more detail).

The mediating variable will be measured by the Parkinson's UK Scale of Perceived Control (PUKSoPC-15; Simpson, Chatzidamianos & Eccles, 2015) and the General Self-Efficacy Scale (GSE-10; Jerusalem & Schwarzer, 1992)

Materials

The survey will contain demographic, clinical and validated measures

Demographic variables:

- Age
- Gender
- Ethnicity
- Work status

- Relationship status
- Living arrangements (alone, co-habiting, residential/nursing home)

Clinical Variables:

- Age of onset
- Time since diagnosis
- Taking medication

Validated Measures:

- The Depression Anxiety and Stress Scale (DASS-21; Lovibond & Lovibond, 1995). This is a well-validated short-form version of the original scale (Henry & Crawford, 2005) and has been used with PD population (Dubrow-Marshall & Birtwell, 2016). The short-version is considered to be more acceptable to

individuals completing the measure (Henry & Crawford, 2005).

- The positive subscale of the Positive and Negative Affect Schedule (PANAS; Watson, Clark & Tellegen, 1988) will be used to measure positive affect in PD in the last few weeks. The positive subscale alone will be used, as the in-depth evaluation of negative mood will be provided by the DASS-21. PANAS is a reliable and valid measure of assessing positive and negative affect in non-clinical populations (Crawford & Henry, 2004).
- The Parkinson's Disease Questionnaire (PDQ-8) will be used to measure quality of life (Jenkinson, Fitzpatrick, Peto, Dummett, Morley et al., 2012).
- The Parkinson's UK Scale of Perceived Control (PUKSoPC-15; Simpson, Chatzidamianos & Eccles, 2015) will be administered. Parkinson's UK members

helped in the development of this scale and it has been initially validated (Simpson et al., 2015).

- Stigma Scale for Chronic Illness (SSCI-24; Molina, Choi, Cella & Rao, 2013) measures both perceived and enacted (carried out) stigma. The SSCI has been validated for use with individuals with neurological conditions, such as PD (Molina, Choi, Cella & Rao, 2013).
- The General Self-Efficacy Scale (GSE-10; Jerusalem & Schwarzer, 1992) will be used to assess individual's general beliefs in their ability to respond and problem solve situations. The scale is a reliable and valid measure for use with individuals experiencing PD (Nilsson, Hagell & Iwarsson, 2015).

Procedure

The project will be advertised through Parkinson's UK website and on the Lancaster University DClinPsy webpage, to enable participants who are not members of Parkinson's UK but identify themselves as having PD, to participate. Participants will read information about the study and will be directed to the consent page. Once they have given their consent to take part in the research the online survey will appear (see appendices for measures attached). Should participants want to complete the survey in a paper format, contact details will appear in the information about the study detailing how they can access a hard copy. Paper copies of the information sheet and the consent form will be provided to individuals who wish to have information in this format. Once the consent form has been returned, a paper copy of the survey will be issued. At the end of the study, participants will be reminded of the

support resources given at the start of the survey. The survey should take approximately 30 minutes to complete. Participants' data will be gathered electronically, and hard copy data will be inputted immediately into the electronic dataset. The hard copies of the questionnaires will be immediately destroyed.

Proposed analysis

The data will be statistically examined using a mediational regression model. Hayes process tool (<http://www.processmacro.org/index.html>), a bias-corrected bootstrap model, will be utilised to conduct the mediation regression.

Practical issues

For individuals who would prefer to access the survey in paper format, an additional cost of postage will be incurred. This will be funded by the DClinPsy course.

Ethical concerns

It is felt that participating in this study will not pose any significant risk to participants or researchers. There is a small risk that participants may become distressed when completing the survey. For this reason, participants will be informed prior to commencing the study that they can stop at any time during survey completion. However, due to the anonymity of participation, their data cannot be removed after they have agreed to take part. The participant information sheet will include sources of support and participants will be reminded of these at the end of the electronic survey.

Service User involvement

Parkinson's UK Patient and Public Involvement group (PPI) members provided their feedback on the participant information sheet and consent form for the study. The

benefit for participants to take part was clarified and changes to wording in the documents were made based on their feedback to aid broad reader access.

Timescale

Ethical approval from Lancaster University Research Ethics Committee will be sought by the principal investigator in June 2017, with a view to the study commencing in September 2017.

Once ethical approval has been granted, liaison with Parkinson's UK will commence to enable the study to be approved by them and advertised via the charity's website (expected September 2017).

It is anticipated data collection will take place between September and December 2017 approximately

Data will be analysed January – March 2018

The study will be written and submitted as part of a doctoral thesis to Lancaster University by May 2018.

Appendices

See attached documents for;

Print screens of electronic participant information sheet and consent form

Participant information Sheet – paper version

Consent form – paper version

Survey materials (demographic, clinical information and validated measures) – paper version

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1.3 Figure 1. Online Survey

Participant Information Sheet



Participant Information Sheet

Stigma, perceived control and wellbeing in individuals with Parkinson's disease

My name is Dani Verity and I am conducting this research as a student in the Doctorate in Clinical Psychology programme at Lancaster University, Lancaster, United Kingdom.

What is the study about?

I am interested in how you experience the attitudes of other people to Parkinson's and any difficulties these might create (stigma), or if these affect how much control you feel you have in your daily life. The aim is to understand the relationship between control, stigma and wellbeing. The findings of the study may be used by practitioners to help inform clinical interventions which may be beneficial for individuals with Parkinson's. They may also help to influence the creation of campaigns to reduce stigma in society.

Why have I been approached?

You have been approached because we need information from people over the age of 18 who identify as having been diagnosed with Parkinson's disease.

Do I have to take part?

No. It's completely up to you to decide whether or not you take part. You can withdraw at any point before submitting the survey. Because your answers will be anonymous, we will be unable to withdraw your details after you have submitted the survey. You have 7 days to complete the survey, after this time you will not be able to edit or input data, and your responses will be automatically submitted.

What will I be asked to do if I take part?

If you decide you would like to take part, you will be asked to complete a survey, which can be accessed online or on paper. Paper copies can be made available upon request (by phone: 07508 406 187, by email: d.verity@lancaster.ac.uk). The survey will ask you questions about your feelings, your sense of control in life with your condition, and the attitudes of others towards you. The online survey does not have to be completed in one sitting. You are able to save your progress.

(when you come to the end of a page, please click the red arrow button below to continue)

A red rectangular button with a white right-pointing arrow and the text "Next" in white.

Will my data be identifiable?

The data you will provide will be entirely anonymous. No one will have access to any personal information that identifies you. Lancaster University will store the electronic data for up to ten years. Information from paper copies will be inputted onto the electronic data source and the paper version immediately destroyed.

What will happen to the results?

The results will be summarised and reported in a thesis which may be submitted for publication in an academic or professional journal and/or presented at conferences. Our findings will be shared with Parkinson's UK in a brief report which will be made available to their members on request. If you would like a copy of the results to be sent to you directly please email d.verity@lancaster.ac.uk.

Are there any risks?

We anticipate no risks will be connected with participation in this study. However, if you experience any distress following participation you are encouraged to contact the resources provided at the end of this sheet.

Are there any benefits to taking part?

Although you may find participating interesting, there are no direct benefits in taking part.

Who has reviewed the project?

This study has been reviewed and approved by the Faculty of Health and Medicine Research Ethics Committee at Lancaster University.

Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact the primary researcher Dani Verity (by phone: 07508 406 187, by email: d.verity@lancaster.ac.uk). The study will be supervised by Dr Fiona Eccles and Dr Jane Simpson at Lancaster University.

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Professor Bill Sellwood
Programme Director, Doctorate in Clinical Psychology
Tel: 01524 593998
Email: b.sellwood@lancaster.ac.uk
Health Research
Lancaster University
Lancaster
LA1 4YG

If you wish to speak to someone outside of the Doctorate in Clinical Psychology programme, you may also contact:

Professor Roger Pickup
Associate Dean for Research
Tel: 01524 593746
Email: r.pickup@lancaster.ac.uk
Faculty of Health and Medicine
(Division of Biomedical and Life Sciences)
Lancaster University
Lancaster
LA1 4YG



Resources in the event of distress

Should you feel distressed either as a result of taking part, or in the future, the following resources may be of assistance:

Parkinson's UK Helpline

Call FREE on 0808 800 0303

Opening times: Monday-Friday: 9am-7pm, Saturday: 10am-2pm
(Closed Sundays/bank holidays)

Email: hello@parkinsons.org.uk

Your GP or Parkinson's Nurse (if available in your area)

Should you experience distress as a result of taking part in this research, we recommend that you seek support from your GP or Parkinson's nurse.

Thank you for taking the time to read this information sheet.

[Please click here if you would like to download a copy of the Participant Information Sheet](#)

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Consent Form



Consent Form

Stigma, perceived control and wellbeing in individuals with Parkinson's Disease

In order to give your consent to take part in the study, please respond to the following questions. If you have any questions or queries before signing the consent form please speak to the principal investigator, (Dani Verity, email: d.verity@lancaster.ac.uk, phone: 07508 406 187).

I have read the information sheet and understand what is expected of me in this study.

Yes

I understand that any responses/information I give will remain anonymous.

Yes

I understand that my participation is voluntary.

Yes

I understand that the information I provide may be discussed with the principal investigator's supervisors at Lancaster University and consent to this.

Yes

I consent to Lancaster University keeping the anonymised data for a period of 10 years after the study has finished.

Yes

I understand that I am free to stop the survey at any point, although any of my data already submitted cannot be removed.

Yes

I consent to take part in the above study.

Yes

(Please click next)



Demographic and Clinical Information



Please answer the following questions about yourself:

1.) How old are you? (Minimum 18 years)

2.) What is your gender?

Male

Female

Other

>>

3.) What age were you when you first noticed symptoms of Parkinson's?

4.) At what age did you receive a diagnosis of Parkinson's?

5.) Are you taking prescribed medication to manage the symptoms of Parkinson's? (please select one option)

Yes

No

I don't know

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6.) What is your ethnic group? (please select one option)

White English

White Welsh

White Scottish

White Northern Irish

White British

White Irish

White Gypsy or Irish Traveller

Any other White background

Mixed White and Black Caribbean

Mixed White and Black African

Mixed White and Asian

Any other Mixed/Multiple ethnic background

Asian British

Asian Indian

Asian Pakistani

Asian Bangladeshi

Asian Chinese

Any other Asian background

Black British

Black African

Black Caribbean

Any other Black/African/Caribbean background

Arab

Other

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7.) Are you currently employed? (please select one option)

Yes

No

Retired

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8.) What is your marital status?

Single

Have a partner

Widowed

Other

<<

>>

9.) What are your living arrangements?

Alone

With others (e.g. partner, children, friends, family)

Residential/nursing home

Other

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Stigma Scale for Chronic Illnesses (SSCI)



Please read the following statements and indicate your level of agreement. Use the key provided.

1	Never
2	Rarely
3	Sometimes
4	Often
5	Always

	1	2	3	4	5
Because of my illness, I felt emotionally distant from other people	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of my illness, I felt left out of things	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of my illness, I felt embarrassed in social situations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of my illness, I worried about other people's attitudes towards me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was unhappy about how my illness affected my appearance	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of my illness, it was hard for me to stay neat and clean	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Because of my illness, I felt embarrassed in social situations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of my illness, I worried about other people's attitudes towards me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was unhappy about how my illness affected my appearance	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of my illness, it was hard for me to stay neat and clean	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of my illness, I worried that I was a burden to others	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt embarrassed about my illness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt embarrassed because of my physical limitations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt embarrassed about my speech	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of my illness, I felt different from others	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I tended to blame myself for the problem	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please continue...

1	Never
2	Rarely
3	Sometimes
4	Often
5	Always

	1	2	3	4	5
I avoided making new friends to avoid telling others about my illness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of my illness, some people seemed uncomfortable with me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of my illness, some people avoided me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of my illness, people were unkind to me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of my illness, people make fun of me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of my illness, people avoided looking at me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Because of my illness, strangers tended to stare at me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**Because of my illness, I was
treated unfairly by others**



**Because of my illness, people
tended to ignore my good points**



**Some people acted as though it
was my fault I have this illness**



**People with my illness lost their
jobs when their employers found
out**



**I lost friends by telling them I have
this illness**



The Parkinson's UK Scale of Perceived Control (PUKSoPC)



Please think about how much each of the following statements applies to you and select the appropriate option. Use the key provided.

1	Not at all
2	Only a little
3	Somewhat
4	Quite a lot
5	Very much

	1	2	3	4	5
I try to focus on the positives in life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I know how to manage my stress levels	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I know how to manage when I'm feeling down	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I know what helps me manage my physical symptoms as much as possible	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I know where to go to find out more information about Parkinson's if I need it	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I know about the different treatment options for Parkinson's	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**I try to engage in social activities
with friends and family when I can**



**I try to take part in activities that
are good for my physical health**



>>

The Depression, Anxiety and Stress Scale (DASS)



Please read each statement and indicate how much it applied to you over the past week. There are no right or wrong answers. Do not spend too much time on any statement. Use the key provided.

0	Did not apply to me
1	Applied to me to some degree, or some of the time
2	Applied to me to a considerable degree or a good part of the time
3	Applied to me very much or most of the time

	0	1	2	3
I found it hard to wind down	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was aware of dryness in my mouth	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I couldn't seem to experience any positive feeling at all	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I experience breathing difficulties (e.g. excessively rapid breathing, breathlessness in the absence of physical exertion)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I found it difficult to work up the initiative to do things	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

I tended to over-react to situations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I experienced trembling (e.g. in the hands)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt that I was using a lot of nervous energy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was worried about situations in which I might panic and make a fool of myself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt that I had nothing to look forward to	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I found myself getting agitated	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

>>

Please continue...

0	Did not apply to me
1	Applied to me to some degree, or some of the time
2	Applied to me to a considerable degree or a good part of the time
3	Applied to me very much or most of the time

	0	1	2	3
I found it difficult to relax	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt down-hearted and blue	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was intolerant of anything that kept me from getting on with what I was doing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt I was close to panic	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was unable to become enthusiastic about anything	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt I wasn't worth much as a person	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I felt that I was rather touchy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

I was aware of the action of my heart in the absence of physical exertion (e.g. sense of heart rate increase, heart missing a beat)

☐ ☐ ☐ ☐

I felt scared without any good reason

☐ ☐ ☐ ☐

I felt that life was meaningless

☐ ☐ ☐ ☐

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The Positive and Negative Affect Scale (PANAS)



This scale consists of a number of words that describe different feelings and emotions. Read each item and indicate to what extent you have felt this way over the past week. Use the key provided.

1	Very slightly or not at all
2	A little
3	Moderately
4	Quite a bit
5	Extremely

	1	2	3	4	5
Interested	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Excited	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Strong	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Enthusiastic	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Proud	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Alert	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Inspired	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Determined	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Attentive	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Active	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

>>

The Parkinson's Disease Questionnaire (PDQ)

Many people with Parkinson's report problems from time to time. We are interested in how you have been in your general health over the last four weeks. Use the key provided.

1	Never
2	Occasionally
3	Sometimes
4	Often
5	Always, or cannot do at all

Over the past four weeks, have you, because of your Parkinson's...

	1	2	3	4	5
... had difficulty in getting around in public places?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... had difficulty dressing yourself?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... felt depressed?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... had problems with close relationships?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... had problems with concentration?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... felt unable to communicate properly?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
... had painful muscle cramps and pains?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Over the past four weeks have you felt embarrassed by having Parkinson's ?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

General Self-Efficacy Scale (GSE)



Please read the following statements and indicate your level of agreement. Use the key provided.

1	Not at all true
2	Hardly true
3	Moderately true
4	Exactly true

	1	2	3	4
I can always manage to solve difficult problems if I try hard enough.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If someone opposes me, I can find the means and ways to get what I want.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It is easy for me to stick to my aims and accomplish my goals.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am confident that I could deal efficiently with unexpected events.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Thanks to my resourcefulness, I know how to handle unforeseen situations.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I can solve most problems if I invest the necessary effort.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I can remain calm when facing difficulties because I can rely on my coping abilities.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
When I am confronted with a problem, I can usually find several solutions.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If I am in trouble, I can usually think of a solution.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I can usually handle whatever comes my way.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



Thank you for taking the time to complete this survey.

If you would like a copy of the results, please contact the researcher, Dani Verity (Email: d.verity@lancaster.ac.uk phone: 07508 406 187)

>>



Resources in the event of distress

Should you feel distressed either as a result of taking part, or in the future, the following resources may be of assistance:

Parkinson's UK Helpline

Call FREE on 0808 800 0303

Opening times: Monday-Friday: 9am-7pm, Saturday: 10am-2pm
(Closed Sundays/bank holidays)

Email: hello@parkinsons.org.uk

Your GP or Parkinson's Nurse (if available in your area)

Should you experience distress as a result of taking part in this research, we recommend that you seek support from your GP or Parkinson's nurse.

1.4 Figure 2. Approval Letter



Applicant: Dani Verity
Supervisor: Fiona Eccles
Department: Health Research
FHMREC Reference: FHMREC16123

15 August 2017

Dear Dani

Re: Stigma, perceived control and wellbeing in individuals with Parkinson's disease

Thank you for submitting your research ethics application for the above project for review by the Faculty of Health and Medicine Research Ethics Committee (FHMREC). The application was recommended for approval by FHMREC, and on behalf of the Chair of the Committee, I can confirm that approval has been granted for this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer at the email address below (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact me if you have any queries or require further information.

Tel:- 01542 592838

Email:- fhmresearchsupport@lancaster.ac.uk

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Diane Hopkins'.

Dr Diane Hopkins
Research Integrity and Governance Officer, Secretary to FHMREC.